



Use of decision aid to improve informed decision-making and communication with physicians on the use of oral complementary and alternative medicine (CAM) among cancer patients on chemotherapy treatment: a randomised controlled trial

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Abstract

Purpose Complementary and alternative medicine (CAM) is often used by cancer patients and is concerning as concomitant oral CAM and chemotherapy use may result in adverse interactions and toxicities. We hypothesise that a decision aid (DA) may promote informed and rational use of oral CAM during chemotherapy, and increase patients' discussion with their oncologists on CAM use.

Methods We randomised 240 patients initiating chemotherapy to receive DA or none. Questionnaires were administered at randomisation (visit 1), 1 month (visit 2) and 3 months (visit 3). The primary endpoint was the decisional conflict score (DCS) for decision made on CAM use during chemotherapy. Secondary endpoints include patients' decision regret score (DRS) on CAM use, CAM uptake, discussion with oncologists on CAM usage, and difference in quality of life (QoL) score between CAM and non-CAM users at visit 3.

Results There was no difference in the mean DCS (mean difference 2.7 [95 CI – 2.9 to 8.3, $p = 0.345$]) and DRS (mean difference – 0.3 [95% CI – 6.3 to 5.8, $p = 0.926$]) between the two arms. There was a reduction in odds of CAM usage in the intervention arm compared to control arm (OR = 0.36, 95% CI 0.17 to 0.78, $p = 0.009$), but there was no difference in discussion with oncologists on CAM usage (OR = 0.46, 95% CI 0.07 to 3.01, $p = 0.419$), or in the QoL between CAM and non-CAM users.

Conclusion Our DA did not reduce DCS among cancer patients on chemotherapy. DA that provides more evidence-based information on CAM, and non-judgemental discussion initiated by oncologists to discuss CAM, may improve its effectiveness.

Keywords Supportive care · Complementary and alternative medicine (CAM) · Decision aid · Quality of life (QoL)

Introduction

Complementary and alternative medicine (CAM) is a group of healthcare practices and products that are not considered

conventional medicine [1]. Globally, CAM is widely used among cancer patients as they sought ways to improve their survival or improve their quality of life during cancer treatment. The prevalence of CAM use is estimated to be 30–50% in the West and appears to be rising over the years [2–4], while it is reported to be 50–60% in Singapore [5–7]. Though compelling evidence is lacking for these unconventional therapies, there have been increasing reports on their role in cancer treatment [8, 9]. For the oncologists, knowledge on CAM use in their cancer patients is paramount as there can potentially be adverse drug interactions between some forms of oral CAM and chemotherapy or possible hazardous effects from the oral CAM [10]. Yet, nearly half of cancer patients in Singapore did not inform their oncologist about oral CAM use during chemotherapy [5] and 85% of oncologists were not aware of their patients' CAM use [7].

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Many studies reported lack of communication between oncologists and their patients regarding CAM usage [11]. However, there were few studies done in an attempt to address this problem. Schofield et al. systematically reviewed 36 studies and recommended guidelines for doctors to discuss CAM with patients [12]. In one of the few randomised studies conducted, community oncology nurses who were in direct contact with patients were educated on the importance of communicating with patients about possible interactions between CAM and conventional treatment. Although the nurses in the intervention group reported they were more likely to ask about CAM usage than did those in the control group, there was no increase in the proportion of patients who reported being asked about CAM use [13].

Decision aids (DA) are evidence-based tools that promote patient participation in treatment decision-making [14, 15] and are used when there is more than one reasonable option to treat a health problem. They provide information on the options, present their risks and benefits, help people to clarify their values, and share them with their healthcare practitioners. It aims to help patients choose healthcare interventions that are congruent with their values, increasing overall patient satisfaction.

We conducted a prospective, open-label, single-centre, randomised controlled trial to evaluate if the use of a DA, in the form of a booklet, can help cancer patients make an informed and rational decision regarding CAM use during chemotherapy, and to determine if a DA can increase the communication between doctors and patients with regard to CAM usage. Indirectly, a DA may also serve to increase patient awareness of the potential benefits and risks with oral CAM usage during chemotherapy, leading them to be more prudent when considering CAM use.

Patients and methods

Study population

The study was conducted at the National University Cancer Institute, Singapore. Eligible patients were cancer patients who were at least 21 years and who were planned for but not yet initiated on chemotherapy. They had to be able to read the DA booklet and complete questionnaires in English, Chinese, or Malay. All cancer types were included and patients on concomitant therapeutic clinical trials were not excluded. Exclusion criteria included cognitive impairment and pre-existing CAM usage. Written informed consent was obtained before any study-related procedures commenced. The study was approved by the ethics committees of the institution and was conducted in accordance with the Declaration of Helsinki and Good Clinical Practice guidelines.

Intervention

Our DA was designed comprising the following four components as recommended by the International Patient Decision Aids Standards (IPDAS) Collaboration [14]: (1) information about chemotherapy and oral CAM; (2) an unbiased review of the possible benefits and risks, including possible interaction with chemotherapy when used concomitantly; (3) a personal worksheet facilitating clarification of own values; (4) structured guidance in decision-making on oral CAM use and promoting discussions with healthcare professionals. We designed the DA in the form of a booklet in English and translated it to the Chinese and Malay languages to cater to patients who could not read English.

Study design

A research assistant approached eligible subjects at the cancer centre to explain the study. Patients who meet the eligibility criteria and who agreed to participate would sign the written informed consent and complete the baseline visit 1 questionnaire that included questions on their demographics, intention to use CAM during chemotherapy, if they discussed CAM use with their oncologists, reasons for considering CAM, and baseline quality of life (QoL) score. Patients were then assigned in a 1:1 ratio to control arm (arm A) or intervention arm receiving DA (arm B) by simple randomisation using a computer-generated random-number sequence. Post-intervention questionnaires were administered 1 month \pm 1 week (visit 2) and 3 months \pm 1 week (visit 3) after visit 1 for all patients. Patients were surveyed for CAM uptake, types of CAM used, if they had informed their oncologists on CAM usage, response from their oncologists, and reasons for non-disclosure of CAM usage to their oncologists at visits 2 and 3. Information on decisional conflict score (DCS) and knowledge on CAM were collected at visit 2 while decision regret score (DRS) and QoL were collected at visit 3. All questionnaires were in English and translated to Chinese and Malay to facilitate self-administration. The DA was unavailable to any patients outside the intervention group during the trial.

Study outcomes

This study focuses on oral CAM usage. Adopting Eisenberg's definition of CAM [1], oral CAM includes dietary and herbal supplements, and 'alternative Medical Systems' such as TCM, *Jamu* (traditional Malay medicine), and *Ayurveda* (traditional Indian medicine).

The primary endpoint of the study is the patients' certainty and satisfaction with the decision made with regard to oral CAM use, measured using DCS at visit 2. It is a validated score that measures patients' perceptions of uncertainty in making a health-related decision and the patients' perceived

effective decision-making, such as feeling the choice is informed, values-based, and expressing satisfaction with the choice [16]. It ranged from 0 to 100, and a higher score on this scale represents more uncertainty and dissatisfaction with the decision made.

The secondary endpoints in this study include regret on oral CAM use during chemotherapy, knowledge score on CAM, the uptake of oral CAM during chemotherapy, the prevalence of communication between patients and their oncologists on oral CAM use, and the difference in QoL of cancer patients who took oral CAM while on chemotherapy compared to cancer patients who did not.

We assessed patients' remorse using oral CAM during chemotherapy using the DRS at visit 3 that ranged from 0 to 100 [17]. It is a validated questionnaire that correlated with decision satisfaction, decisional conflict, and overall QoL; a higher score reflects higher regret with the decision made. As there is no validated questionnaire to assess patients' knowledge of CAM, we designed a brief questionnaire consisting of 7 questions to measure their knowledge of CAM at visit 2. QoL of the patients was measured using the European Organisation for Research and Treatment of Cancer (EORTC) QLQ-30 version 3.0 [18], a widely utilised questionnaire that consists of 3 components, the functional scales (FS), symptom scale (SS), and global health status. These scales range from 0 to 100; a higher score for FS and global

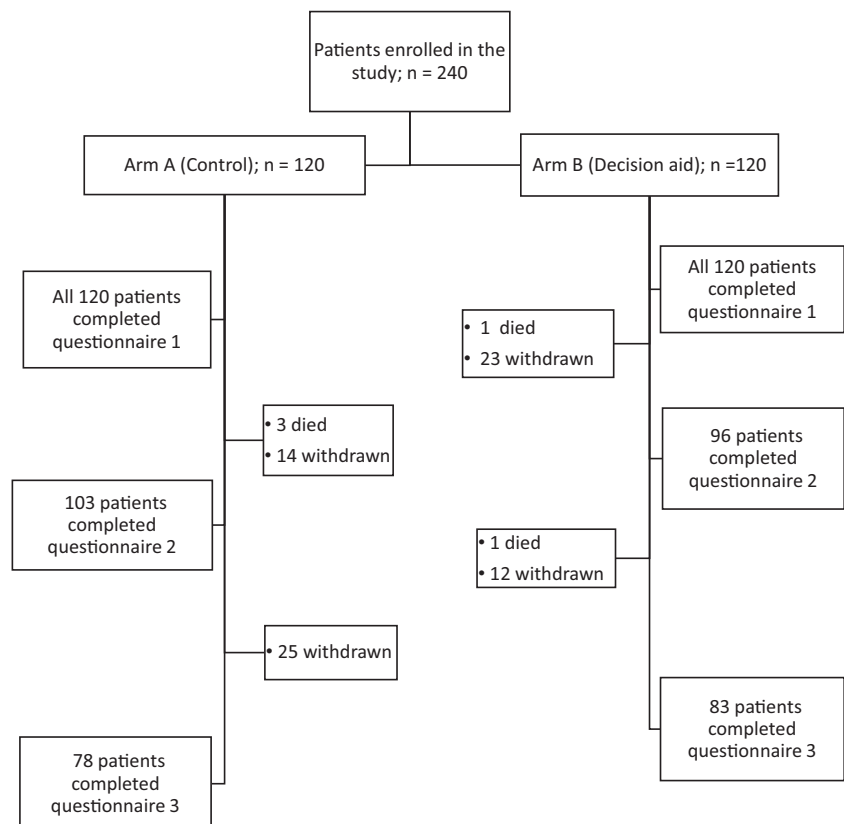
health status indicates a better level of functioning while a higher SS score denotes a higher level of symptoms. We surveyed patients' QoL at baseline and visit 3.

Statistical analyses

Before the study, we conducted a pilot study with 20 patients and determined the mean DCS before intervention was 18. We hypothesised that intervention would result in a 30% reduction in this score, and hence a mean score of 12.6 was postulated for the intervention arm. Assuming a SD of 13.4, with a two-sided alpha of 0.05 and a power of 80%, the required sample size was 100 patients per group. We targeted to recruit 120 patients per arm after accounting for a 20% dropout rate [19].

Descriptive statistics were used to compare the characteristics of the intervention and control groups. We compared the mean difference in DCS and DRS between the intervention and control group using independent *t* test. The generalised estimating equation (GEE) assuming the binomial family of distribution with logit link function was implemented for the analysis of secondary outcomes involving CAM usage and discussion with oncologists, considering possible intra-subject correlation in the outcome responses at visits 2 and 3. Adjustment was further made for the respective baseline covariates and the effect of time. The analysis of covariance (ANCOVA) was used to

Fig. 1 CONSORT diagram



compare all the domains of EORTC QLQC-30 between the CAM and non-CAM users, adjusting for the respective baseline covariates. All statistical analyses were performed using SPSS version 26.0, assuming a two-sided test at 5% level of significance based on the principle of intention-to-treat.

Results

Between Oct 2014 and Jan 2019, 240 patients were enrolled in the study, with 120 patients each randomised to control (arm A) and intervention (arm B). In arm A, 103 (85.8%) and 78 (65%) patients completed the questionnaires at visits 2 and 3 respectively while in arm B, 96 (80%) and 83 (69.1%) patients completed the questionnaires at visits 2 and 3 respectively. Overall, a total of 37 (15.4%) patients withdrew from the study by visit 2, and another 41 (17.1%) withdrew by visit 3. Withdrawals were due to lost to follow up or refusal to continue participation. Five patients did not complete the study as they had passed away (Fig. 1). Both arms were balanced with respect to baseline patient characteristics (Table 1). A majority of the patients were female (67.9%) and Chinese (63.8%) and had stage 4 cancer (32.9%).

Decisional conflict score, decision regret score, and knowledge score

There was no difference in the primary endpoint of mean DCS at visit 2 between the observation and intervention arms (34.2 for arm A vs. 36.9 for arm B, with mean difference of 2.7 (95% CI - 2.9 to 8.3), $p = 0.345$). The secondary endpoint of DRS at visit 3 was also similar between the two arms, with a mean score of 22.0 in arm A and 21.7 in arm B and mean difference of - 0.3 (95% CI - 6.3 to 5.8, $p = 0.926$). There was no difference in knowledge score at visit 2 between the 2 arms (54.6 for arm A vs. 59.2 for arm B, mean difference of 4.6) (95% CI - 3.2 to 12.3, $p = 0.244$) (Table 2).

Oral CAM usage

Seventy-two patients considered oral CAM use at baseline (39 in arm A; 33 in arm B), 22 reported actually taking oral CAM at visit 2 (15 in arm A; 7 in arm B), and 19 reported taking oral CAM at visit 3 (14 in arm A; 5 in arm B). There was a reduction in the odds of CAM usage in the intervention arm as compared to the control arm (OR = 0.36, 95% CI 0.17 to 0.78, $p = 0.009$), and this difference remained significant adjusting for the respective baseline covariates and the effect of time (Table 3). Traditional Chinese medicine (TCM) either prescribed by a practitioner or bought over the counter (OTC) and vitamins and supplements were the most popular oral CAM considered for use by patients at baseline and taken at subsequent visits (Table 4). Patients were surveyed for

Table 1 Patient demographics and clinical characteristics

	Arm A (control), <i>n</i> = 120	Arm B (decision aid), <i>n</i> = 120
Median age (range)—years	58.4 (22–75)	55.0 (29–83)
Gender—no. (%)		
Male	37 (30.8)	40 (33.3)
Female	83 (69.2)	80 (66.7)
Race—no. (%)		
Chinese	76 (63.3)	77 (64.2)
Malay	19 (15.8)	27 (22.5)
Indian	12 (10.0)	5 (4.2)
Other	13 (10.8)	11 (9.2)
Highest education—no. (%)		
Primary school	26 (21.7)	28 (23.3)
Secondary school	48 (40.0)	45 (37.5)
Junior college/polytechnic	11 (9.2)	22 (18.3)
University	35 (29.2)	25 (20.8)
Annual income—no. (%)		
< \$30,000	89 (74.2)	88 (73.3)
\$30,000–\$60,000	17 (14.3)	20 (16.7)
\$60,000–\$100,000	8 (6.7)	8 (6.7)
> \$100,000	6 (5.0)	4 (3.3)
Cancer site—no. (%)		
Breast	47 (39.2)	42 (35.0)
Gastrointestinal	23 (19.2)	27 (22.5)
Gynaecological	16 (13.3)	18 (15.0)
Head and neck	7 (5.8)	6 (5.0)
Hepatobiliary	5 (4.2)	6 (5.0)
Lung	14 (11.7)	14 (11.7)
Urological	7 (5.8)	3 (2.5)
Others	1 (0.8)	4 (3.3)
Stage—no. (%)		
1	15 (12.5)	19 (15.8)
2	32 (26.7)	29 (24.2)
3	36 (30.0)	30 (25.0)
4	37 (30.8)	42 (35.0)
Intention to consume CAM during chemotherapy	39 (32.5%)	33 (27.5%)

reasons for considering oral CAM use and could provide more than one reason. Among the 126 responses obtained from the 72 patients who considered oral CAM use at baseline, the most common reason was to boost immunity during chemotherapy (31.7%), followed by enhancing treatment outcomes (31.0%), improving general well-being (23.0%), and reducing side effects from chemotherapy (11.9%).

Discussion of CAM usage with oncologist

Twenty patients informed their doctors on their intention to use oral CAM at baseline (13/39 [33.3%] in arm A vs. 7/33

Table 2 Summary of outcome measures

	Arm A (control), <i>n</i> = 120		Arm B (decision aid), <i>n</i> = 120		Mean difference	95% CI of the difference	<i>p</i> value
	Mean	SD	Mean	SD			
Primary outcome							
Decisional conflict score (DCS) at 1 month	34.2	17.7	36.9	22.2	2.7	− 2.9 to 8.3	0.345
Secondary outcomes							
Knowledge score at 1 month	54.6	28.3	59.2	27.2	4.6	− 3.2 to 12.3	0.244
Decision regret score (DRS) at 3 months	22.0	17.8	21.7	20.7	− 0.3	− 6.3 to 5.8	0.926

[21.2%] in arm B), while 11 patients (8/15 [53.3%] in arm A vs. 3/7 [42.9%] in arm B) and 12 patients (11/ 14 [78.6%] in arm A vs. 1/5 [20%] in arm B) informed their doctors on their actual CAM use at visit 2 and visit 3 respectively. There was no difference between the 2 arms with respect to discussion with oncologists on CAM usage (OR = 0.46, 95% CI 0.07 to 3.01, *p* = 0.419) (Table 3). The result was not materially altered even after adjusting for the respective baseline covariates and the effect of time.

The most commonly cited reason for non-disclosure at baseline was that their doctors did not ask (15/52 [28.8%]), while at visit 2, it was the anticipation of opposition by their doctors (4/11 [36.4%]). By visit 3, more than 50% of patients did not discuss their CAM use with their oncologist as they felt that it was a personal decision that need not involve their oncologists. Among the patients who discussed intended CAM use with their oncologists at baseline, 50% (10/20) faced opposition while the remaining 50% (10/20) received neutral responses. At subsequent visits 2 and 3, the majority of patients (56.5% [13/23]) who discussed their actual CAM use with their oncologists received neutral responses, while 17.4% (4/23) had encouragement and 26.1% (6/23) faced opposition.

QoL

We performed a pre-specified subgroup analysis to compare the QoL of the 19 patients who took CAM vs. 142 non-CAM

Table 3 Effect of intervention on CAM usage and discussion with doctor

Outcome/ model	OR	95% CI	<i>p</i> value
CAM usage			
Unadjusted	0.36	0.17 to 0.78	0.009
Adjusted*	0.38	0.18 to 0.82	0.014
Discussion with doctor			
Unadjusted	0.46	0.07 to 3.01	0.419
Adjusted*	0.67	0.09 to 5.28	0.708

*Adjusted for the respective baseline covariate and the effect of time

users at visit 3, and there was no difference in all the functional scales, symptom scales, and global health status. However, there was a trend towards higher symptom scales in the CAM users for symptoms such as fatigue, nausea/vomiting, pain, dyspnoea, insomnia, and diarrhoea, implying CAM users had more symptoms compared to non-CAM users (Table 5).

Discussion

DAs are effective in improving the decision-making process for patients who face cancer-related decisions, ranging from cancer screening to cancer treatment and prevention [15, 20]. Disappointingly, the primary endpoint of our study was not met.

One possible reason as to why our DA did not reduce patients' DCS nor their DRS was that we could not ensure that patients randomised to the intervention arm read the booklet given. Another postulated reason is that we addressed the different types of CAM broadly in our DA, and the information provided may be inadequate to help patients make an informed decision. This is supported by the lack of significant improvement in CAM knowledge in the patients in our intervention arm compared to the control arm. Recently, a multi-disciplinary group developed a DA in the form of a website for parents of children with cancer, and found that parents wanted evidence on CAM to be included in the DA. Since there are more than 1800 CAM modalities and it was not feasible to perform systematic reviews on all childhood cancer-related complaints, the group focused solely on CAM use for pain during childhood cancer [21]. The incorporation of more evidence-based data and focus on a specific CAM or condition may improve the effectiveness of our DA. In addition, our DA was intended as an adjunct to patients' discussion with their oncologists on CAM use and was not meant to replace counselling by a healthcare professional. As not all patients in our study discussed CAM use with their oncologists, this may have negated the effectiveness of the DA. The higher than expected drop-out rates by visit 3 may have

Table 4 Types of CAM considered by patients at baseline and subsequently taken at 1 month and 3 months post randomisation

Types of CAM1	Arm A (control)			Arm B (decision aid)		
	Considered taking at baseline, <i>n</i> = 52	Taken 1 month later, <i>n</i> = 15	Taken 3 months later, <i>n</i> = 15	Considering at baseline, <i>n</i> = 40	Taken 1 month later, <i>n</i> = 7	Taken 3 months later, <i>n</i> = 6
TCM2 prescribed	16 (30.8)	1 (6.7)	2 (13.3)	22 (55)	2 (28.6)	2 (33.3)
TCM OTC3	5 (9.6)	2 (13.3)	2 (13.3)	4 (10)	0	1 (16.7)
Vitamins and supplements	13 (25.0)	5 (33.3)	6 (40)	9 (22.5)	3 (42.9)	1 (16.7)
Special diet	9 (17.3)	2 (13.3)	2 (13.3)	3 (7.5)	1 (14.3)	0
Traditional Malay medicine (Jamu)	5 (9.6)	0	1 (6.7)	0	0	0
Others	4 (7.7)	5 (33.3%)	2 (13.3)	2 (5)	1 (14.3)	2 (33.3)

¹ Each patient may choose more than 1 type of oral CAM

² TCM, traditional Chinese medicine

³ TCM OTC, traditional Chinese medicine bought over the counter

reduced the power of our study. Lastly, with easy access to wealth of information in this digital age, it is plausible that the patients in the control arm may have obtained information from other sources to help them decide on oral CAM use. This in turn reduced the difference in the DCS and DRS scores between the two arms. Nonetheless, the lower uptake of actual oral CAM use in the intervention arm may have been due to the increased awareness of the potential toxicities and interaction with chemotherapy through the use of DA.

Though 30% of our patients were considering CAM usage at baseline, the actual uptake in oral CAM at subsequent visits was low at less than 10%. The much lower than expected

uptake of CAM is in contrast to previous studies that reported the prevalence of CAM usage in cancer patients to be about 30–60% [5–7] and may be due to several reasons. Firstly, we excluded patients who were already using CAM or who have decided on CAM usage. Secondly, we focused on oral CAM use concomitant with chemotherapy, while previous studies evaluated the prevalence of CAM use in all cancer patients, regardless of the treatment they were on. Thirdly, this study was conducted at a tertiary cancer centre, and patients on therapeutic clinical trials were not excluded; these patients may have been advised against using CAM, although a previous study reported that 34% of patients still consumed herbs

Table 5 Unadjusted and adjusted mean difference (95% CI) in QoL scores 3 months after randomisation, between CAM (*n* = 19) and no-CAM users (*n* = 142)

Domain	Unadjusted	<i>p</i> value	*Adjusted	<i>p</i> value
Functioning scales				
Physical functioning (PF)	1.00 (− 8.20 to 10.20)	0.830	3.55 (− 4.86 to 11.97)	0.406
Role functioning (RF)	− 0.62 (− 14.10 to 12.86)	0.927	− 1.55 (− 13.92 to 10.82)	0.805
Cognitive functioning (CF)	− 7.32 (− 17.52 to 2.88)	0.159	− 6.94 (− 16.70 to 2.82)	0.162
Social functioning (SF)	2.84 (− 10.80 to 16.48)	0.681	− 1.20 (− 13.49 to 11.08)	0.847
Emotional functioning (EF)	− 6.76 (− 17.30 to 3.78)	0.207	− 8.04 (− 17.45 to 1.37)	0.094
Symptom scales				
Fatigue (FA)	− 0.60 (− 13.01 to 11.81)	0.925	1.51 (− 10.02 to 13.03)	0.797
Nausea and vomiting (NV)	2.49 (− 6.87 to 11.85)	0.600	4.44 (− 4.78 to 13.67)	0.343
Pain (PA)	9.50 (− 2.41 to 21.42)	0.117	10.51 (− 1.06 to 22.08)	0.075
Dyspnoea (DY)	3.65 (− 6.23 to 13.53)	0.467	4.92 (− 4.75 to 14.59)	0.317
Insomnia (SL)	3.34 (− 12.32 to 19.00)	0.674	4.28 (− 10.74 to 19.31)	0.574
Appetite loss (AP)	− 0.12 (− 15.97 to 15.73)	0.988	− 0.22 (− 15.18 to 14.74)	0.977
Constipation (CO)	− 1.77 (− 11.76 to 8.23)	0.727	− 0.878 (− 10.77 to 9.01)	0.861
Diarrhoea (DI)	8.35 (− 2.36 to 19.5)	0.125	8.99 (− 1.55 to 19.54)	0.094
Financial difficulties (FI)	3.12 (− 14.14 to 20.39)	0.722	− 4.94 (− 19.86 to 9.98)	0.514
Global health status				
Global health status	2.35 (− 8.51 to 13.21)	0.669	2.70 (− 8.09 to 13.49)	0.622

*Adjusted for the respective baseline domain scale

and dietary supplements while participating in phase I clinical trials [22].

The oral CAM used most commonly in our study was TCM, consistent with earlier local studies [5, 7, 23]. This is not unexpected as the majority of Singaporeans are Chinese and this is similarly observed in Taiwan and Hong Kong with a predominantly Chinese population [24, 25]. The use of TCM raises particular concerns due to the potential for herb-drug interactions, and these interactions are more likely to occur unknowingly as most TCM contains a mixture of different herbs and chemicals, most of which patients are not able to identify. Similar to the findings by Shih et al., nearly a third of our patients considered oral CAM to boost their immunity during chemotherapy, and another one quarter wanted to improve their general well-being [7]. This reflects the common perception among cancer patients that chemotherapy ‘weakens their body’ and their desire to counteract it.

Less than one-third of patients who intended to take oral CAM discussed with their oncologists at baseline though the proportion of patients who discussed actual CAM usage with their oncologists increased at subsequent visits to 50% and 63% at visits 2 and 3 respectively. Previous studies showed that patients had attributed their non-disclosure mainly to the lack of questioning about CAM by their doctors [26, 27]. This is concordant with our study findings, where the most common reason cited at baseline was that doctors did not ask. While oncologists tend to follow up on cancer-related decisions that impact patients’ treatment at consults, the discussion on CAM usage is not seen as a priority during consults and is in part influenced by the oncologist’s lack of knowledge on CAM and his level of concern about the safety of CAM use. On the other hand, at visit 3, the most commonly cited reason for non-disclosure was that it is a personal decision. The general perception that oncologists do not know much about CAM as it is not within their expertise may have contributed to patients making their own decision on CAM use without involving their oncologists. Again, this highlights the importance of proactive initiation of discussion by oncologists with their patients on CAM usage in a non-judgemental manner. This creates an opportunity for oncologists to help patients make an informed decision on CAM usage, and oncologists should consider setting aside time during consults to discuss this important topic with their patients.

We found that there was no difference in QoL in CAM users compared to non-CAM users. We acknowledged that there were few CAM users, limiting statistical power. There was a trend towards higher symptom scales in CAM users suggesting that patients who were symptomatic from their cancers and treatment tend to turn to CAM use in an attempt to improve their symptoms, though it is similarly plausible that CAM usage causes toxicities that increased patients’ symptom burden.

To our knowledge, this is the first randomised controlled trial that evaluated the role of a DA to help patients decide on

CAM usage during chemotherapy. The sample size is large at 240 patients and represents one of few published randomised trials that aim to address a common and important problem of CAM usage in cancer patients. We acknowledge several limitations to this study. As there is no validated questionnaire to measure a patient’s knowledge of CAM, we designed a brief questionnaire for the study that may not be sensitive enough to detect differences in the patient’s knowledge. Pre-intervention knowledge score was also not assessed in our study; thus, we could not compare changes in knowledge scores between the 2 arms. We also did not have adequate measure of compliance in the intervention arm. Although we factored in drop-outs of 20% in the calculation of sample size, the actual drop-out rate was higher than expected, reducing the power of our study.

In conclusion, this is the first randomised trial that attempts to evaluate the role of a DA to help patients make an informed decision on CAM use. Though our study yielded negative results, future strategies to improve effectiveness of a DA in this setting include the incorporation of more focused evidence-based information on CAM, and non-judgemental active invitation by oncologists to discuss CAM use at subsequent consults. This could be explored further in future studies.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s00520-020-05872-5>.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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