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Varieties of silence – a mixed-methods study exploring reasons and justifications for nondisclosure of the use of complementary therapies to physicians in Finland

Pauliina Aarva^{1*}, Tiina Väänänen¹, Maija Pyykkönen² and Tiia-Tuulia Kankkunen³

Abstract

Background In health care, two in three users of complementary therapies (CT) stay silent about their CT use. Disclosure of CT use to physicians is important for patient safety, participation, and shared decision-making. Common reasons for CT nondisclosure include patients' expectations of physicians' unaccepting response to disclosure, physicians not asking, and patients believing it is unnecessary. This study aimed to increase understanding of patient silence. We investigated how the reasons for nondisclosure of CT use reported by CT users were associated with the frequency of CT disclosure and how these associations and reported justifications to keep silent reflect patient silence among the study participants.

Methods This mixed-methods study used existing data from the non-probability-based online survey (n=6802) targeted to CT users among the general population in Finland. A qualitative structured tabular thematic analysis was conducted for the selected 342 brief texts describing the reasons and justification for not telling physicians about CT use. The associations between the frequency of CT disclosure and the reasons for CT nondisclosure were analysed by crosstabulations and binary logistic regression analysis with SPSS (v28).

Results Three types of patient silence were revealed. Avoidant silence illustrates the respondents coping with the fear of unwanted response from a physician and avoiding the expected negative consequences of CT disclosure. Precautionary silence exemplifies respondents striving to prevent the reoccurrence of previously experienced frustration of wishes to be seen and heard as CT users. Conditional silence portrays the self-confidence of respondents who assessed their need to disclose CT use to physicians on a case-by-case basis.

Conclusions Silence, for some patients, may serve as a way of warding off past and possible future fears and frustrations related to CT disclosure. It is important to recognise different types of patient silence related to CT disclosure to enhance patient participation and shared decision-making in health care. Efforts are needed to provide

*Correspondence: Pauliina Aarva pauliina.aarva@gmail.com

Full list of author information is available at the end of the article



health policy decision-makers with information about CT users' lived experiences with CT communication in health care.

Keywords Complementary therapies (CT), Complementary and alternative medicine (CAM), Disclosure of CT, Reasons, Justifications, Mixed-methods study, Patient silence, Finland

Introduction

"This is a song about the inability of people to communicate with each other." – Art Garfunkel [1].

There are at least two types of silence clinicians should be aware [2]. The first is a therapeutic silence, and the second is an avoidant silence, which Simon & Garfunkel's ballad 'Sound of Silence' illuminates [1, 2]. In clinical encounters, patients may stay silent unintentionally, or they may deliberately choose not to talk.

In health care, two in three users of complementary therapies (CT) stay silent about their CT use, the disclosure rates ranging from 7 to 80% between countries and studies [3]. The three most common reasons for CT nondisclosure include expectations of the physician's unaccepting response to disclosing [3-5], the physician not asking or not being interested, and the patients themselves believing it is not important or necessary to inform about the healing modalities used outside the conventional health care system [3]. CT users who perceive benefits from CT seem more likely to disclose CT use to their healthcare provider [6-8]. Disclosure is also associated with patient-centred care [9], the quality of patientprovider communication [10–12], access to and quality of conventional care [13] and trust between patients and physicians [14, 15].

Patient silence, i.e., the patient's perspective on CT nondisclosure may reflect patients' difficulties to communicate with physicians. The incongruence of world views and different interpretations of the consequences of CT are suggested to be associated with the disclosure of CT use [16, 17]. Also, CT users may feel disempowered or silenced by biomedicine [18] and to fall into 'mainstream marginality' in society [19].

However, the possibility of being more than a silent patient encompasses the importance of articulating personal meaning and having that meaning heard by another person, which may serve to ascertain a person's experiences and views as valid and valuable [18]. On the other hand, the disclosure of CT use to a physician is suggested as an important proactive health behaviour that reflects a commitment to continued use of CT as a healthcare option [6–8]. The consumer commitment approach suggests that reasons for CT disclosure include the positive outcomes and the symbolic values of CT users, such as an individual sense of control over health, a holistic view of healing and the value of naturality. According to the consumer commitment approach, disclosing CT use to a physician may be viewed as a symbolic act that reinforces

one's identity with respect to being someone who uses CT [6–8].

As an empirical research object, silence is said to 'resist analysis' while it can, however, be read as the trace of something that allows interpretations [20]. Sometimes, silence is considered one 's reasonable, valuable, and right action to allow one to maintain respect for one's personal values and meaning in life under silencing situations [21]. Sometimes, it can be seen as a resource and perceived as a sign of resilience, but it may also reflect confusion, alienation, or anomie [22, 23].

Disclosure of CT use to physicians is regarded as important for different reasons. First, combined use of natural remedies with prescribed medicine may cause toxic herb-drug interaction effects (e.g. St John's Wort with certain anticoagulant drugs) or other harmful adverse effects, such as therapeutic failure of prescribed medicine [24]. Homoeopathic aggravation (i.e. transient worsening of the patient's symptoms) has also been reported as an adverse effect [25]. To ensure patient safety, physicians must know whether patients use natural remedies or other CT modalities that might produce adverse effects [26–29].

Second, the experienced benefits of patients' CT use may remain undiscussed in clinical encounters. These benefits include experienced general helpfulness [30, 31], management for pain [32, 33] and perceived improvement of well-being and quality of life [34]. Third, CT use is common all over the world [35–39], CT modalities are applied to a large extent for health promotion [40, 41] and CT is used primarily to supplement conventional health care rather than replace it [36]. Thus, communication about CT use is critical to patient participation, patient-centred care [10, 42–47] and integration and coordination of care [11, 48, 49].

Earlier studies on CT disclosure focused largely on specific diseases or patient groups, such as older adults [14, 50], cancer [11, 16, 51–53], cardiovascular diseases [8], different treatment situations, for example, haemodialysis [54]. Most of the earlier studies provided quantitative data [3]. Quality of patient-clinician communication have been studies also using qualitative methods [12, 50, 55]. Mixed-methods studies revealed e.g., CT disclosure rates or reasons for nondisclosure of dietary supplements [56, 57] and childrens´ CT use [58, 59]. Our mixed-methods study adds to the current research literature information on how CT users among the general population justify

their nondisclosure and how the justifications reflect patient silence.

Justifications, reasons, and beliefs are closely related in everyday discourses, each having different connotations in different contexts [60, 61]. Therefore, in this study, we define justification as an acceptable reason for doing something that justifies an act or way of behaving, showing something to be right or reasonable by a person. 'Right' and 'reasonable' refer here to silence expected to bring personal benefits for CT non-disclosers. Following a critical realist ontology, we treat the reported experiences and knowledge as mediated and constructed through language, while acknowledging material and social structures that generate them [62]. The theoretical premise of this study is that CT disclosure behaviour is a form of health behaviour, and nondisclosure can be unintentional or deliberate [7, 22] About the sharing of information between a patient and a physician about CT use, we use, depending on context, the terms 'tell', 'disclose', 'communicate', 'discuss', 'report', or 'speak' [63]. 'Study participants' and 'respondents' are synonymously used in this article.

Finland is a Nordic welfare state with strong public trust in medical authorities and science institutions [64]. Universal access to most conventional healthcare services with minimal or no direct cost to patients is ensured [65], with the challenge of improving continuity of care, in particular, the continuity of the patient-general practitioner (GP) relationship in primary care [66] . Physicians' attitudes are divided between more acceptance towards some CT modalities, such as acupuncture and more scepticism towards others, such as reiki [67]. The prevalence of CT use in the general Finnish population is 51%, including self-help practices, visits to therapists, an natural remedies, excluding vitamins and minerals [31].

In public discourse, CT remain controversial, and the boundary between official medicine and its 'outsiders' is sharp [68–70]. There is no consensus on what terms should be used when discussing about CT that are offered outside conventional health care to clients. Users and service providers widely adopt the terms 'natural therapies' and 'health products' [71], while Finnish government documents prefer the term 'alternative therapies' [72]. Different CT terminology is used also globally in professional and scientific publications, such as complementary and alternative medicine (CAM) [73–75]. We chose for this article the term CT, because these modalities are primarily used to supplement conventional health care rather than replace it [36].

This study aimed to increase understanding of patient silence and CT users' justifications for keeping quiet about their use of CT. We answer the research question on how the reasons for deliberate nondisclosure of CT use were associated with the frequency of disclosure

and how these associations and reported justifications to keep silent about CT use reflect patient silence among the study participants.

Methods

Participants and sampling

We utilised existing data extracted from the non-probability-based online survey targeted to CT users among the general population in Finland. The survey was organised by a joint non-governmental organization of citizens and CT professionals and three professional CT associations [71]. It was open to anyone to respond between the 8th of October and the 15th of December 2021 on the platform of the Finnish Ministry of Justice's (MoJF) Democracy Services. These services aim to facilitate civic influence and citizen participation by offering accessible services for various citizen groups [76]. To recruit participants, the survey organisers placed invitations to follow a MoJF link to the survey questionnaire on several social media platforms, from which anyone interested in distributing information about the survey could further share it.

The recruitment method, river sampling, allowed the organizers to reach internet respondents who voluntarily selected themselves for participation. This non-probability sampling method is suggested to attract disproportionately large numbers of subpopulation members, but it does not statistically represent the population or even a specific subgroup [77]. Altogether, 6,802 individuals responded to the survey. Due to the recruitment method, the sample remained a convenience sample.

Questionnaire

The survey included 15 closed-ended and four openended questions about user experiences, such as reasons for not disclosing CT use to a physician, combined use of CT and conventional health care, views on how respondents would like CT to be utilised in conventional health care and perceived helpfulness of various CT modalities. The research results of perceived helpfulness were reported earlier [34]. The questionnaire was in Finnish [71]. In this study, we analysed the answers to the two survey questions. For the close-ended Question 1 (Fig. 1) three response options 'Yes, almost always,' 'Only rarely,' 'Never' were proposed. The follow-up Question 2 was open-ended (Fig. 1).

Regarding demographics the answers to the following two close-ended questions were used in the analysis: 'What is your gender'? with four response options: man, woman, other, 'I do not want to answer', and 'What is your age?' with seven response options: 17 years or under, 18–29 years, 30–44 years, 45–59 years, 60–69 years, 70 years and over, and I do not want to answer. Year of birth or respondent's exact age in years were not asked.

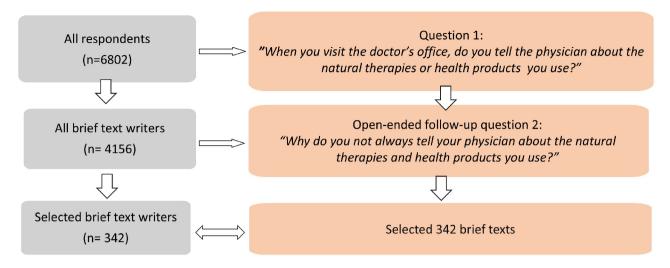


Fig. 1 Two survey questions on CT disclosure analysed in this study and the number of respondents to each question

Quantitative measures and analysis

Gender was merged into three categories: men, women and other; the latter included responses 'Other' and 'I do not want to answer'. Age was merged into four categories: 44 years or below, 45-59 years, 60 years or over and no answer ('I do not want to answer'). The youngest and the oldest age groups were small compared to others. The number of respondents 17 years or below was 6 (0,09%), 29 years or below was 584 (8.6%), and 70 years or above was 477 (7%) of the total number of respondents (n=6802). Gender, age and frequency of disclosing the CT use to physician ('Yes, almost always, 'Only rarely, 'Never') were used for the crosstabulations of the full data set (n=6802). The same variables were used in crosstabulations of the coded qualitative material, i.e., the selected set of brief texts written by 342 respondents to describe the respondents' characteristics (Fig. 1; Table 1). IBM SPSS Statistics (version 28) was used for the quantitative analysis.

Extraction of the qualitative data

Among all 6802 respondents there were 4156 people who answered to the open-ended question 2 (Fig. 1). These answers consisted of short texts of one or a few words up to entries of 250 words. The average length was 15 words. The data included a large number of very short comments, such as 'Attitude', 'No time', 'Nobody asks,' and 'I always tell'.

For the analysis, we chose from 4156 brief texts those with a minimum length of 20 words. We excluded from the analysis the comments that did not verbally justify the expressed reason for nondisclosure of CT use. We randomly selected every tenth brief text for qualitative thematic analysis with the following selection criteria:

- 1. Text had to provide verbal justifications for CT nondisclosure in more detail than just a few words.
- 2. The length of the chosen text had to be 20 words at the minimum.
- 3. Every 10th text corresponding to criteria 1 and 2 was selected.
- 4. If the 10th text did not fit criteria 1 and 2, the next appropriate text nearest to the selection point was selected.

Following this procedure, we ended up with 342 brief texts, accounting for 8.2% of the total brief texts in our sample.

Analysis of the qualitative data

Once we had familiarised ourselves with the data set of 4156 brief texts and done preliminary open coding regarding reasons for nondisclosure of CT use to a physician, we constructed the codebook of seven themes of reasons. Six of them were selected from the previous research results of the systematic review, which revealed reasons for CT nondisclosure [3]. One theme 'Case-by-case assessment of the medical encounter' was added based on our preliminary coding exercises. The seven themes are listed in Table 2. The qualitative analysis process, including the codebook development, is detailed in Supplementary Materials.

In the second step, the first author conducted a structured tabular thematic analysis for the selected 342 responses using the codebook. Structured tabular thematic analysis offers an illustrative qualitative method for analysing brief texts in a structured way [78]. To ensure the rigour of the analysis, we checked inter-analyst agreement by recoding 60 brief texts. Each of the three co-authors coded separately 20 randomly selected brief texts. The inter-analyst agreement was 78.9%.

Table 1 The respondents' characteristics, including the total sample (n = 6802) and the sample of brief text writers (n = 342), gender, age, and frequency of disclosing CT use to a

Gender and age	Number of r	Number of respondents who reported	ed always, only rarely	and never disc	always, only rarely and never disclosing their CT use to a physician $(\%, n)$	o a physician	(%, n)		
	Total sample $(n=6802)$	(n=6802)				Sample of k	Sample of brief texts writers $(n = 342)$	2)	
	All % (n)	Almost always % (n)	Only rarely $\%$ (n) Never $\%$ (n) No answer $\%$ (n)	Never % (n)	No answer % (n)	All % (n)	Almost always $\%$ (n) Only rarely $\%$ (n)	Only rarely % (n)	Never % (n)
	100 (6802)	46.5 (3160)	37.1 (2522)	8.4 (570)	8.0 (546)	100 (342)	32.5 (111)	57.6 (197)	9.9 (34)
Gender*									
Women	87.7 (5968)	47.1 (2808)	37.4 (2232	7.6 (452)	8.0 (476)	87.7 (300)	32.3 (97)	57.3 (172)	10.3 (31)
Men	10.3 (700)	42.3 (296)	34.3 (240)	14.7 (103)	8.7 (61)	9.4 (32)	37.5 (12)	53.1 (17)	9.4 (3)
Other	2.0(134)	44.8 (60)	37.3 (50)	11.2 (15)	6.7 (9)	2.9 (10)	20.0 (2)	80.0 (8)	0 (0)
Age groups*									
44 years and below **	35.8 (2438)	44.3 (1079)	41.8 (1018)	9.3 (226)	4.7 (115)	42.1 (144)	32.6 (47)	61.8 (89)	5.6 (8)
45-59 years **	39.6 (2692)	48.9 (1316)	35.3 (951)	7.7 (208)	8.1 (217)	34.8 (199)	32.8 (39)	49.6 (59)	17.6 (21)
60 years and over **	24.0 (1632)	45.9 (749)	33.0 (539)	8.1 (132)	13.0 (212)	21.6 (74)	33.8 (25)	59.5 (44)	6.8 (5)
No answer	0.6 (40)	50.0 (20)	35.0 (14)	10.0 (4)	5.0.(2)	1.5 (5)	(0) 0	1.5 (5)	(0) 0

** In the quotes of this article, the age of the respondents is presented with the terms young (44 years and below), middle-aged (45–59 years) and older (60 years and over) 'Gender and age groups in the total sample (6802)<0.001, age groups in the sample of brief texts writers (n=342) p=0.013

The third step comprised the quantitative analysis, i.e., crosstabulations (Table 2) and binary logistic regression analysis (Table 3) of the coded qualitative data (n=342). For this, the frequency of CT disclosure was merged into two categories: 'Almost always' and 'Rarely or never'. The latter included answers 'Only rarely' and 'Never'. We created crosstabulation tables and performed x2-tests to assess the associations between the disclosure status ('Almost always' vs. 'Rarely or never') and the reported reasons for nondisclosure (Table 2). Then, we investigated the associations between seven variables for the CT nondisclosure, i.e., each of the themes of reasons for CT nondisclosure mentioned in the brief texts and the disclosure status, using binary logistic backward regression analysis. Odds ratios (OR) and 95% confidence intervals (CI) are presented in Table 3. The table including all seven variables used in the regression analysis is presented in Supplementary Materials.

In the fourth step, we interpreted how the reported justifications for CT nondisclosure reflect the types of patient silence revealed by the regression analysis. Illustrative quotations provide examples of types of patient silence and reported justifications for keeping silent about CT use.

Ethical considerations

Although the data collection method presents no ethical concerns, there are some potential issues that should be mentioned. First, the questionnaire included an ethically problematic structured question about respondents' age. One of the seven age categories was presented in a form of "17 years or below". Due to this kind of formulation, there is no information about how young those 6 respondents were who chose this age category. Second, linguistic equality was not fully considered. Even though the second official language in Finland is Swedish with around 288 000 speakers (of 5,6 million population), the questionnaire was offered only in Finnish. The questionnaire was neither offered in Saami languages. There are around 10,500 Saami people, the only indigenous people in Finland, living in Northern part of the country [79].

The researchers were not involved in the planning of the internet questionnaire. They accessed the data on the written request four months after the data collection was completed. Therefore, the prior ethical approval for this study was not possible to obtain from the academic ethics committee of the Tampere region (See section Declarations). The owners of the data, four non-governmental associations, and the MoJF providing platform for the survey questionnaire ensured confidentiality and anonymity. The survey collected no personal information: name, contact details, socio-economic status, education, occupation or place of residence. Neither did the questionnaire include questions on personal health. The

Table 2 Themes of reported reasons for nondisclosure of CT use to a physician in respondents' brief texts and reported frequency of disclosure. (n = 342)

Theme of reported reasons for nondisclosure of CT use to a physician	All respondents	Respondents disclosing CT use to a physician almost always and rarely/never			
	n=342	Disclosed almost always n = 111	Disclosed rarely or never n=231	р	
	% (n)	% (n)	% (n)	_	
1. Expectations of physician's attitudes and response	47.4 (162)	34.2 (38)	53.7(124)	< 0.001	
2. Expectation of physician's knowledge of CT	31.0 (106)	28.8 (32)	32.0 (74)	0.548	
3. Previous experiences with CT disclosure	20.8 (71)	15.3 (17)	23.4 (54)	0.085	
4. CT use not related to medical care/disclosure not considered necessary	32.0 (109)	40.5 (45)	27.8 (64)	0.018	
5. Shortness of time/did not come to mind	14.4 (49)	10.8 (12)	16.1 (37)	0.193	
6. Case-by-case assessment of the medical encounter	15.2 (52)	24.3 (27)	10.8 (25)	0.001	
7. Safety, risks and adverse effects of CT	4.4 (15)	4.5 (5)	4.4 (10)	0.960	

Table 3 The results of binary logistic regression analysis on the association between the reasons of CT nondisclosure and the disclosure status (almost always vs. rarely or never). The binary logistic backward regression analysis, the final model, p < 0.05, odds ratios (OR) and 95% confidence. (n = 342)

Themes on reasons for nondisclosure of CT use that entered into the	Respondents disclosing	OR	95% CI	
final model	almost always (n = 342) % (n)		From	То
Expectations of physician's attitudes and response (Theme 1)	47.4 (162)	0.43	0.27	0.70
Previous experiences with CT disclosure (Theme 3)	20.8 (71)	0.52	0.28	0.97
Case-by-case assessment of the medical encounter (Theme 6)	15.2 (52)	2.35	1.27	4.35

questionnaire did not include any background or other questions, which could be considered sensitive information. Of the respondents' background information, only age and gender were asked.

Participation in the survey was voluntary, and anyone with internet access could answer, and could stop answering at any time. Respondents did not receive compensation for their participation in this survey. Responses could be submitted only once from a particular IP address to prevent repeated survey completion by the same individuals. Only qualified persons from the MoJF hade/have access to IP addresses.

The researchers are committed to complying with the ethical principles of the the Finnish National Board on Research Integrity (see section Declarations). No one of the four researchers works as CT practitioner. Only the researchers contributing to this study and the survey organizers had access to the data, which was stored on password-protected network drives and computers during the research project.

Results

Respondent characteristics

Women accounted for 87.7% both of the total sample (n=6802) and brief text writers (n=342). Respondents in the sample of brief text writers were younger than those in the total sample. Slightly less than half of all respondents (46.5%) and a third (32.5%) of brief text writers

indicated that they almost always told the physician about their CT use, while 8.4% of all respondents and 9.9% of brief texts writers reported never telling. ((Table 1.

The seven themes of reasons for nondisclosure of CT use

The structured tabular thematic analysis of the selected 342 brief texts revealed seven themes of reasons for the nondisclosure of CT use (Table 2).

Theme 1. Physician's attitudes and response Nearly half of the respondents (47.4%) mentioned in their brief texts that they did not tell physicians about their CT use, because they expected physicians to show a negative attitude towards CT or respond inappropriately. The number of those with expectations of physicians' negative responses was statistically significantly higher among rarely or never disclosers (53.7%) than among almost always disclosers (34.2%).

Respondents reported being afraid that the physician would demean the CT user or might even forbid them from using certain modalities. Others reminded that physicians' expected unwillingness to encounter patients as emotional and communicative human beings hindered disclosure. For example, a young woman (age groups are presented in Table 1) wrote: "I can't bear to listen to arrogant disrespect and name-calling as a gullible fool who puts their health in danger by eating something that

has no effect yet is still dangerous. I'd rather be silent, so I won't feel as bad after seeing the doctor."

Theme 2. Expectations of physician's knowledge on CT Slightly less than a third (31%) of all respondents wrote about physician's insufficient knowledge or understanding of CT. No statistically significant difference was found between the groups of almost always and rarely or never disclosers. Nondisclosure was described by proactively emphasising that physicians could not understand that CT could positively impact patients' lives. Respondents referred to differences between physicians and their own understanding of healing concepts, such as 'energy' and 'holism', to discrepancies in world views and to criticism of Western medical practices.

Respondents' reported lived experiences indicated that nondisclosure might reflect a shying away from worldview-dissonances that could potentially undermine core belief systems for both parties. This point may mean different ideological positions [22] concerning health and healing. The critique of Western medicine was primarily targeted at the pharmaceutical industry's power in health care. Some wrote that CT nondisclosure, in general, is related to current treatment practices that favour prescription medication over nonpharmaceutical healing methods. For example, an older woman (age groups are presented in Table 1) formulated her opinions as follows: "It is a common knowledge that medics are very strongly under the obligation to pharmaceutical industry. When a doctor graduates, he can only make a prescription. Doctors are specialized on ophthalmology, orthopaedics, gynaecology etc. but they are not seeing a patient as whole. Doctors see themselves above the patient, they make prescription and re-schedule new appointment in few weeks. If one medication is not working, then it is changed to another".

Theme 3. Previous experiences with CT disclosure Every fifth brief text writer (20.8%) referred to the previous experiences with CT disclosure as a reason for nondisclosure. There was no statistically significant difference between the two discloser groups. Feelings of disappointment and frustration as a result of previous communication experiences were reflected in the texts about getting inadequate responses from a physician. Some said that disclosure could negatively influence the quality of medical care and physician-patient relationship. A middle-aged man (age groups are presented in Table 1) described his experiences: "I have noticed that the medical professionals attitude towards me changes when I have mentioned the use of natural treatments or health products. It has had a negative effect to the treatment I've received."

Others emphasised that because they had previously experienced that physicians did not see or hear them

as CT users, they did not want again to receive belittling or other negative comments about healing methods they themselves considered helpful. A young woman portrayed her concerns: "I don't need to hear irrelevant comments about the treatments that had helped my family and decreased the need of seeing the doctor or use of medicine."

Theme 4. CT use not related to medical care The number of those who reported CT use unrelated to medical care or disclosure not considered necessary was statistically significantly higher among almost always disclosers (40.5%) than among rarely or never disclosers (27.8%). According to respondents, they did not discuss CT use in medical consultations because they did not expect CT use to have much bearing on the type of treatments prescribed by their physicians or regarded CT as health promotion rather than medical care. For example, a young woman noted: "I usually go [to the doctor] just for a specific illness or ailment, like eczema or an infection. With natural treatments, I maintain my health by reducing stress and increasing the relaxation and well-being of the body and mind with various massages or other procedures."

Respondents who considered disclosure of CT use irrelevant or unnecessary seemed to consciously navigate between the worlds of medical care and CT therapies. A middle-aged woman noted that it is not necessary to disclose, because, in her opinion, 'nutritional supplements do not affect healing of a sprain or removal of a fat pad'. Another middle-aged woman emphasised the importance of her own knowledge and mentioned: "I know better what treatments and health products work for me. I decide what I do and what products I use. I am not giving the power of decision to doctor."

Theme 5. Shortness of time Respondents (14.4%) referred in their brief texts also to lack of time during consultations or forgetting to bring up their CT use. They mentioned that physicians did not ask and pointed out that the patient would not tell if the physician would not ask. According to a young woman: "Nowadays doctors don't ask anything. Patient doesn't know what he should tell, and doctor doesn't ask... ".

Theme 6. Case-by-case assessment of the medical encounter Those respondents (15.2%) who wrote about case-by-case assessment of the medical encounter pointed out that each encounter with a physician was weighed and reevaluated separately. They reported that raising the subject of CT use in a discussion with a physician depended on the physician or the quality of the encounter. The number of those who reported their case-by-case assessments was statistically significantly higher among almost always disclosers (24.3%) than among rarely or never disclosers

(10.8%). Responses on the reasons for nondisclosure typically started with a phrase: 'It depends on...', for example an older woman explained: "It depends on doctor. For some doctors you can tell... Some doctors, especially young ones, deny alternatives so strongly that I'd rather say nothing."

The decision depended also on the assessment of the individual encounter with a physician. A middle-age man wrote: "I would tell if I feel that it matters on that situation and if I feel (my intuition) that the doctor is a person to whom I want to tell this kind of matter. I need to feel that I will be heard openly without judgement or being despised."

In addition to the doctor-related reasons to stay silent, respondent's decisions to discuss specific CT modalities were based on the type of CT, in particular the physician's assumed reaction to the modality in question. A young woman specified her selective approach: "I talk about acupuncture, bone setting and health products, but not often about energy healing and homeopathy, for example. Especially energy healing seems to be like a curse. When you talk about energy healing you will be undermined and classified to second-class citizen, you even face nearly hostile attitude."

Theme 7. Safety, risks and adverse effects of CT These issues did not emerge as a prominent topic for the respondents, with 4.4% of writers mentioning them as a reason for nondisclosure. Drug-herb interactions, however, were mentioned concerning respondents' reliance on the physicians' expertise and their responsibility to ask about CT use. For example a young woman expected physician to be active in this respect: "Patients can't be expected to know when to bring up these issues. Doctors should always ask about the use of health products if there is a known combine effects with medicine."

The three types of patient silence: avoidant, precautionary and conditional

In the final model of the backward stepwise logistic regression, the likelihood of disclosing CT use to a physician was associated with three themes of reasons for nondisclosure of CT use (Table 3).

Those who indicated assessing on a case-by-case-basis whether to disclose were more than twice as likely to disclose their CT use to a physician compared to those who did not mention a case-by-case assessment in their brief texts. Those who reported their expectations of physician's attitudes and responses and those who wrote about their previous experiences with CT disclosure as reasons for CT nondisclosure were slightly less likely to disclose their CT use to physicians compared to those who did not mention these themes. (Table 3). See Supplementary Materials for more details on regression analysis.

Based on the regression analysis results we concluded that there are three types of patient silence that are significant in our data. We named these silences as avoidant, precautionary, and conditional. (Fig. 2).

Avoidant silence

In our data avoidant silence seemed to help respondents cope with the fear of the assumed physician's negative attitude and response to CT disclosure. Fear led to the decision to avoid possible bad consequences, such as undesirable, unpleasant emotions caused by hurt feelings. The logic of staying silent is that if physicians do not know that patients use CT, patients need not be afraid of feeling hurt or ashamed, which the physician's assumed negative response was expected to bring along. The silence was thus justified by a reluctance to face unpleasant feelings and expected negative consequences of CT disclosure.

According to the data, unwillingness to speak can be interpreted as a sign of respondents' situational inability to communicate with physicians, which results in the decision to remain silent instead of articulating their own experiences and views on CT use. Avoidant silence thus illustrates the communicative distance between the patient and physician, which may reflect a power imbalance between them.

Another type of justifications for avoidant silence referred not so much to individual physicians' possible negative response as to society's dominant social norms. These are reflected in public discourse, where many CT modalities are located outside or at the margin of health care and are interpreted as odd or not socially acceptable in society and tend to be viewed with suspicion [68–70]. For example, a middle-aged woman described her views: "[I do not tell] because treatments have been condemned, 'demonized' or people using them are declared delusional or stupid like frail and retarded. I consider myself an 'intelligent' person with academic education, I don't take well such a strong critic on decisions one makes."

Precautionary silence

Precautionary silence, according to our data, allowed respondents to avoid previously felt frustration of wishes to be seen and heard as CT users. It may have helped maintain respect for one's personal values as well as protect one's integrity, self-esteem, and identity as a person who has chosen to use CT. A quotation of a young woman illustrates how patient's previous experiences may become an obstacle to discussing CT use with a physician: "[I do not tell because] my choices have been judged and my feelings been invalidated before... I know how I feel and about my health better than a doctor."

During the next medical consultation, this woman might stay silent to prevent a similar situation.

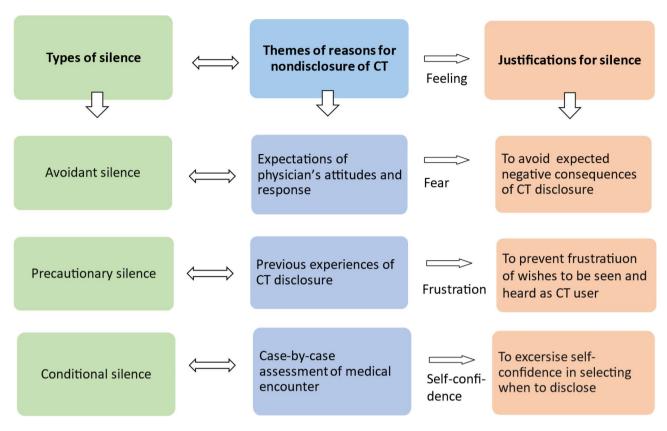


Fig. 2 Three types of patient silence, themes of reasons, and justifications for nondisclosure of CT in 342 brief texts of CT users in Finland

Precautionary silence in our data also refers to possible taboos regarding unwritten rules and unspoken social norms that define what is suitable and acceptable to discuss in health care. An older woman argued that because "[CT] are not part of contemporary medicine ..., they are not allowed subjects to discuss."

Conditional silence

According to our data, conditional silence can be interpreted as a selective patient approach. Exercising self-confidence in choosing between disclosure and nondisclosure of CT use to a physician refers to trust and belief in one's own ability to make the right choices. Reflected in justifications for nondisclosure, selectivity indicates that respondents' own assessments of the quality of medical encounters were used as a guide for decision-making on disclosure. For example, freedom to choose one's GP was emphasised when referring to quality of encounters. In case the physician's behaviour did not allow respondents to freely discuss their CT use, respondents might even change physicians, although it might be challenging in publicly funded health care in Finland [65, 66]. An older woman emphasised her selective approach in the following way: "If a physician expresses opposition to the treatments in question [CT], I will go to another physician. Luckily, some physicians have a holistic view.".

In sum, conditional silence illustrates respondents' proactive health behaviour, sense of control over health and care options, and the will to make independent decisions on CT disclosure.

Discussion

This study explored the associations of the frequency of CT disclosure to a physician with the reported reasons for nondisclosure in a convenience sample of 342 CT users and the justifications for keeping silent about CT use in medical consultations.

The results demonstrate that the respondents reporting case-by-case assessments of medical encounters as a reason for CT nondisclosure were statistically significantly more likely to tell physicians about their CT use (OR 2.35, 95% CI from 1.26 to 4.38). In contrast, those mentioning expectations on physician's attitudes and responses (OR 0.43, 95%, CI from 0.26 to 0.70) and those mentioning previous experiences with CT disclosure (OR 0.52, 95%, CI from 0.28 to 0.97) were less likely to discuss their CT use with physicians.

The results provide new insights into nondisclosure of CT use to physicians. We revealed three types of silence. The first type, avoidant silence may help patients distance

themselves from and cope with their fear of anticipated physician's negative reactions to CT disclosure. The second type, precautionary silence, allows patients to prevent the reoccurrence of previously experienced frustration of wishes to be seen and heard as CT users. The third type, conditional silence, portrays the self-confidence of patients when disclosing CT use to physicians on a case-by-case basis. Self-confidence may serve as the facilitator for better communication between patients and physicians. Patients' willingness to talk about their CT use instead of keeping silent potentially drives connection and dialogue with physicians.

Our results on respondents' self-confidence to choose, when, what, and to whom to disclose CT use point to patient's active role in treatment as well as to a sense of control over health, similarly as shown in the previous US population study [7]. The findings also confirm the results of earlier studies on the importance of physicians' attitudes and responses and the role of patients' previous experiences with CT disclosure [3]. They indicate that a physician's accepting and nonjudgemental approach might promote a patients' self-confidence in striving to exchange experiences and views with physicians about anything important for a patient. Hence, we suggest that supporting patients' self-confidence may enhance proactive disclosure behaviour and open dialogue about CT use in health care. Furthermore, it is important to increase the exchange of patient experiences and knowledge related to CT use.

In our data, respondents kept silent, particularly in the case of CT modalities that are most disputed in society and least accepted by medical professionals, such as homoeopathy and energy healing. At the same time, the use of acupuncture, meditation or traditional Finnish Kalevala bone-setting was more openly shared with a physician. The public discourse on CT as ineffective, unscientific and not safe [68–70]. both reflects and constructs public opinion, which, combined with the discursive power of the medical profession, probably influences how and what people disclose to physicians.

The results indicate that silence may be due to the unspoken dominant norms and implicit communication rules in medical encounters. Such norms and rules in the health care system favour argumentation based on biomedical knowledge, evidence of efficacy, and expertise over experiential knowledge of CT users [18, 68]. In the biomedical context, diseases, symptoms, and their biological causes tend to matter more than a person's views, feelings and experiences on healing [18]. In such a context, CT nondisclosure is logical because some CT users do not find it necessary – as shown in this study – to disclose their healing experiences that do not matter to physicians' understanding of health care.

Considering the value of patients' privacy and deliberate decisions not to want to share information about CT use with physicians, silence can be understood as right and rational behaviour. CT users may perceive CT disclosure to the physician as irrelevant, unnecessary, or unimportant because they may use CT to supplement the treatments their physicians prescribe. Moreover, they may regard CT as health promotion and disease prevention rather than medical care. It is also important to notice that patients may strongly rely on medical expertise and, therefore, do not disclose, expecting physicians to ask about CT use.

Safety, risks, and adverse effects did not emerge as prominent topics in our data, which is probably explained by the mixed-methods design of this study. Safety, risks, and adverse effects may gain more attention in studies where they are proposed as clear answer options in structured questionnaires [3].

The study has limitations. Firstly, online river sampling may potentially exclude subpopulation members who are non-familiar with internet use and online surveys. Although this point might not be a likely limitation due to the high internet coverage in Finland [80], a potential limitation may be that the less active people and those less advanced in modern communication technology remain less involved in responding than other population groups.

Secondly, the survey probably did not reach those CT users who did not disclose their CT use due to their experienced adverse effects. The topical self-selection in the data collection may have influenced, as very few respondents mentioned the adverse effects. People responding to the current survey may have been pro-CT users with mostly positive experiences with CT and a critical attitude to disclosing CT to physicians. Therefore, respondents might have expressed their positive views on CT and critical views on CT disclosure more often than the average CT users or those with less positive outcomes of CT use might have. The almost full absence of those reporting about adverse effects in their brief texts may also be related to the tendency of people to inform less about their bad CT experiences, as shown in the US population study suggesting that those patients with less positive outcomes of the CT use would be less likely to share their use with general practitioners [7].

Thirdly, the numeric data based on two samples (Table 1) are unlikely to accurately represent the population group of CT users in Finland because the conclusions drawn from the non-probability sample are inevitably limited [77]. However, the results accurately reflect the rationale and argumentation of three types of silence in the specific subgroup of CT users who wrote brief texts about the reasons for CT nondisclosure. Furthermore, the reasons for nondisclosure mentioned by

the respondents in this study are largely similar to those revealed in other studies [3].

Fourthly, the data used in this study were gathered by a joint non-governmental organization of citizens and CT professionals and three professional CT actors outside the scientific community. The respondents may have included not only CT users but also CT practitioners. Indeed, although the respondents were not asked about their education or occupation, some explicitly reported in their brief texts that they are either registered health professionals or CT practitioners with personal experience of CT use. This point may have influenced how the reasons for nondisclosure were described in the brief texts.

Fifthly, as the questionnaire was only in Finnish, the voice of people speaking any minority languages, such as Swedish and Saami, could not be heard in this study.

Finally, the vast majority (87.7%) of the respondents in our study comprised women. At the same time, in the representative sample, the weighted proportion of females in the group of CT users in Finland was 58.5% [31]. 'Historical tendencies towards trivialising women's experience' [18] combined with the feminisation of the CAM [69] may be linked to the women's eagerness to participate in this survey to get their marginalised voice heard better than it is perhaps heard in the health care system.

Implementation of the findings

The findings can be implemented in improving communication practices in health care, which would enhance CT users and physicians see each other as partners with the common goal of patient well-being, even when their knowledge, experiences, values, and views on CT differ.

Further research

For future research, it is important to examine the alignment of patients' and physicians' perspectives on CT communication with a focus on specific safety concerns. Patients' proactive CT disclosure behaviour to be examined in the context of health promotion warrants further attention in health research. It would also be useful to validate our results of a mixed-methods study in representative population samples. Finally, considering the three silences as a theoretical background, it would be useful for improving communication in medical encounters to assess to what extent biomedicine's symbolic or real-life power and influence of public discourse in media and social media affect the disclosure behaviour of CT users.

Conclusions

The study revealed three types of patient silence related to the nondisclosure of CT to physicians. Avoidant silence may help CT users keep away from anticipated unpleasant feelings due to expected physician's negative response to CT disclosure. Precautionary silence may assist in prevention of reoccurrence of previously experienced frustration of wishes to be seen and heard as CT user in clinical encounter. Conditional silence may strengthen patients' self-confidence in selecting what, when and whom to tell about their CT use. Avoidant and precautionary silences illustrate that CT users can manage their fears and frustrations related to CT disclosure. Conditional silence portrays CT users' self-confidence in clinical consultations to select on a case-by-case basis between disclosure and nondisclosure of their CT use to physicians.

Patient silence in clinical encounters may reflect communicative distance between patients and physicians. To reduce the distance, CT users must be encouraged to initiate discussions about their CT use with physicians. At the same time, physicians must acknowledge CT users' values, worldviews, and experiences as a source of knowledge and information while considering the professional knowledge of evidence-based medicine.

Our findings suggest that to improve patient-centred care, it is important to recognise various types of patient silence in health care. For the further development of shared decision-making in health care, it is important to facilitate patient participation, open dialogue and recognition of patients' experiences with CT use. Efforts are also needed to provide health policy decision-makers with information about CT users' lived experiences in CT communication in health care.

Abbreviations

CT Complementary therapies

CAM Complementary and alternative medicine

GP General practitioner MoJF Finnish Ministry of Justice

Supplementary Information

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Supplementary Material 1

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Author contributions

PA and TV prepared a conceptual framework. T-TK and PA performed a preliminary analysis. MP and PA performed the statistical analyses. All authors participated in the qualitative analysis. PA wrote the initial version of the

manuscript with tables and figures. All authors reviewed subsequent versions and read and approved the final manuscript.

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Data availability

All datasets and materials are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

The study was conducted in adherence to the Declaration of Helsinki. An informed consent to participate in the survey was obtained from each respondent. Participants were appropriately informed about the survey, and the content and purpose of the study were explained to participants. Participation was voluntary. Thus, completing the questionnaire was considered as informed consent for participation. This survey collected no personal data that would allow to identify individual participants. This study does not cause any potential risks or harm to survey respondents, and it meets the ethical requirements of research with human participants according to The Finnish National Board on Research Integrity guidelines [81]. The ethical approval was deemed unnecessary by the Academic Ethics Committee of the Tampere region. According to a statement from the Academic Ethics Committee of the Tampere region, Finnish legislation and above-mentioned guidelines ethical approval is not required for surveys that do not collect personal data which could be directly or indirectly used to identify a person or persons, taking into account the means that are reasonably likely to used to do so. According to these guidelines and the statement from the Academic Ethics Committee of the Tampere region the researcher must request an ethical review statement from a human sciences ethics committee, if their research contains any of the following: (a) Participation in the research deviates from the principle of informed consent (the participation is not voluntary or the participants are not given sufficient or correct information about the research), (b) the research involves intervening in the physical integrity of research participants, (c) the focus of the research is on minors under the age of 15, without separate consent from a parent or carer or without informing a parent or carer in a way that would enable them to prevent the child's participation in the research, (d) research that exposes participants to exceptionally strong stimuli, (e) research that involves a risk of causing mental harm that exceeds the limits of normal daily life to the research participants or their family members or others closest to them or (f) conducting the research could involve a threat to the safety of participants or researchers or their family members or others closest to them . Our research does not contain any of the aforementioned factors, and thus it meets the ethical requirements of research with human participants in Finland.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

Author details

¹Faculty of Social Sciences, Tampere University, Tampere, Finland ²Socon – Social and Health Consultants Ltd, Tampere, Finland ³Philosophical faculty, University of Eastern Finland, Joensuu, Finland

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