Adaptation of a peer based online emotional support program as an adjunct to treatment for people with schizophrenia-spectrum disorders

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\textbf{A B S T R A C T}

The aim of this study was to describe the adaptation of a program designed to leverage 7 Cups of Tea (7Cups), an available online platform that provides volunteer (i.e., listener) based emotional support, to complement ongoing treatment for people with schizophrenia-spectrum disorders. The adaptation of the program was based on two stages: First, following platform demonstration, six clinicians specializing in the treatment of schizophrenia completed a survey examining attitudes towards the program and suggested modifications. In response to clinicians' feedback, a computerized training program that provides information for listeners supporting people with schizophrenia was developed, and one hundred and sixty eight listeners completed an online knowledge test. In the second stage, 10 outpatients with schizophrenia-spectrum disorders were recruited to chat with listeners, provided post-session open-ended comments as well as usability and usefulness ratings assessed on a five point Likert scale. The additional training significantly increased listeners' knowledge and confidence (0.38 \leq Cohen's d \leq 1.14, p < 0.024). Patients' attitudes towards the listeners were positive and they expected the platform will be usable and helpful. Most patients expected a positive gain by having the opportunity to receive an outlet for emotions and socialize. The authors conclude that the use of an available digital platform resulted in a feasible intervention in terms of cost and availability, which is now ready for evaluation in real-world settings.

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1. Introduction

Social and emotional support are considered to be important factors in determining the coping process, feelings of competence and well-being of people with schizophrenia-spectrum disorders (Bengtsson-Tops and Hansson, 2001; Buchanan, 1995; Eack et al., 2007; Erickson et al., 1998; Ritsner et al., 2000; Yanos et al., 2001). The importance of psychosocial interventions aimed at providing such support is sustained by studies showing that pharmacological treatment alone may not suffice for illness management (Buchanan et al., 2010; Kane, 1995). However, lack of trained staff or limited funding limit the availability of these interventions (Drake et al., 2009). This notion provides a call for programs to introduce additional resources of social and emotional support for people with schizophrenia-spectrum disorders, which are both cost effective and easy to implement in real-world conditions.

One way to overcome barriers of cost and lack of trained staff is to develop programs that leverage inexpensive human resources, such as non-professional-assisted interventions (Kazdin and Blase, 2011; Kazdin and Rabbitt, 2013). While studies have shown positive outcomes from the use of peer support programs (Ahmed et al., 2012; Chinman et al., 2014; Davidson et al., 2006) and family psychoeducation for people with schizophrenia (Dixon et al., 2000; Randolph et al., 1994), their effect is still limited by the need to develop and implement practical methods to engage, screen, train, and refer non-professionals to promote service assimilation and reach.

Technology-based interventions for people with schizophrenia have already demonstrated promising outcomes in reducing accessibility barriers, promoting service utilization (Ben-Zeev, 2012; Ben-Zeev et al., 2014), successfully engaging people with family supporters (Rotondi et al., 2010) and providing a social network of peers (Alvarez-Jimenez et al., 2013). It seems that technology could also introduce feasible solutions to screening, training, and connecting non-professionals with those in need of just in time support.

7 Cups of Tea (7Cups) was chosen for this study since it offers such a solution. The 7Cups platform trains volunteers (i.e., listeners) to provide free online emotional support, and then engages them with interested users. A previous study focusing on 7Cups users demonstrated high user satisfaction with 84.6% of users positively perceiving the listener they had chatted with. The study also showed that, on average, users...
who indicated previous experience with psychotherapy evaluated their listeners’ emotional support to be as helpful as psychotherapy (Baumel, 2015). While these findings may imply positive outcomes from the utilization of volunteer-based emotional support they represent subjective opinions of people who already enjoy that service. It is not certain, thus, how a clinically diagnosed population being referred to this kind of support will perceive the service, whether they will find it useful, and under which circumstances.

In this paper we describe the development process of SUPPORT, a program to provide online volunteer-based emotional support based on 7Cups platform as an adjunct to treatment for people diagnosed with schizophrenia-spectrum disorders. This program aims to respond both to costs and implementation barriers mentioned above by leveraging an available platform, inexpensive human resource, and scalable methods to train and engage non professionals with those in need of their support.

2. Methods and results

The development and evaluation of SUPPORT was based on two stages that followed an overview of 7Cups and adaptation of safety practices for vulnerable populations (Sharkey et al., 2011). In the first stage, we gathered clinicians’ feedback and examined the efficacy of an additional computerized training program for listeners developed in response to this feedback. In the second stage, we referred patients to chat with a trained listener and examined platform usability and attitudes towards the program and the listeners. Study procedures for both stages were approved by the Feinstien Institute Review Board.

2.1. Overview of 7Cups

7Cups is a web- or app-based messaging system that provides volunteer-based emotional support (7 Cups of Tea website, 2015). Listeners are required to complete a computerized training course on active listening (Rogers and Farson, 1957) before being able to respond to chat requests (see Fig. 1 for main screenshots of user/listener interaction).

Upon logging into the platform, users can choose who they would like to chat with from a list of available listeners (see Fig. 1). Users who wish to chat with the same listener can do so by agreeing on a mutual time to chat, or by leaving the listener a message that she or he can later respond to through the platform’s internal messaging system. Users can also view listeners’ page in order to receive some information about the listener including the listener’s country, age group they listen to, preferred topics for chats (e.g., parenting), and experience on the platform (e.g., number of chats conducted). Users can additionally see the listener’s average rating scores on 1 to 5 point scale covering several domains (e.g., Helpfulness, Professionalism), based on ratings provided by users who chatted with the listener in the past.

2.1.1. Safety practices

SUPPORT follows recommended safety practices for internet based intervention research that involves vulnerable populations (Sharkey et al., 2011) and relates to system security, online and clinical safety (see Table 1 for finalized safety features). Online safety is managed with accordance to U.S. Department of Health & Human Services guidelines and 7Cups system security was reviewed and approved by the IT risk management team of Feinstein Institute for Medical Research, part of NS-LIJ health system.

7Cups is anonymously based and users have to confirm that they are not in crisis before beginning the chat. A banner is presented on screen with help links available for crisis situations, and listeners are directed to refer users to more intense programs or other resources in cases of need (Baumel, 2015). Based on previous work done within The Zucker Hillside Hospital, a large mental health center in New York, and in accordance with internet based intervention studies that relate to safety concerns for people with history of psychosis (Alvarez-Jimenez et al., 2013; Gleeson et al., 2014) it was decided that the following populations will be excluded from participation: (a) patients with suicidal or homicidal intent, and (b) patients that did not achieve remission from acute psychosis.

2.2. Stage 1: Adjusting 7Cups to supplement the treatment for people with schizophrenia-spectrum disorders

2.2.1. Clinician feedback

The lead author met separately with 6 clinicians specialized in the treatment and rehabilitation process of people with schizophrenia-spectrum disorders (4 psychiatrists, 2 clinical psychologists). The aim of these meetings was to gather feedback regarding ways that volunteer-based, online emotional support could be used as an adjunct to other treatments for patients with schizophrenia-spectrum disorders. At the beginning of the meeting, the lead author demonstrated the 7Cups platform, explained the listeners’ training, how members engage listeners, and encouraged the clinicians to ask any clarifying question. At the end of the demonstration, the clinicians were asked to answer a survey containing close-ended questions regarding the use potential of SUPPORT using a 5 items Likert scale ranging from strongly disagree (1) to strongly agree (5). The survey also consisted of open-ended questions regarding the way this service could complement ongoing treatment, specific populations who might greatly benefit from utilizing this program, and further recommendations for program modification. Clinicians were instructed that this input was part of a larger research program to refer patients to use this service as an adjunct to other ongoing treatments.

2.2.1.1. Clinicians’ responses

Clinicians’ responses to closed ended questions are presented in Table 2. All clinicians reported expecting a positive gain from referring people with schizophrenia-spectrum disorders to receive volunteer-based online emotional support. They stated that this program has the potential to support patients in between clinical meetings, improve patient outcomes, and also help patients engage in therapeutic activities. Some clinicians were neutral regarding the ability of this kind of platform to make it easier for people with schizophrenia to socially engage with other people.

All clinicians stated that online emotional support could be helpful by providing a resource for contacting other people and socializing ("patients without a network of connections will be able to talk about their difficulties with people different from clinicians’; “This is essentially people from the community. it fosters the idea that people care for one another”) and some suggested it might be a step forward in reducing social isolation by providing some training before socializing within their community (“It may really help facilitate engagement and help them eventually go back into the community”; “If they practice socialization online, hopefully they will be able to use these skills to socialize in their real world”). Respondents also stated that this support might provide patients with an outlet for emotions, which many of them are lacking within the outpatient setting (“Most patients meet with the psychiatrist and don’t receive ongoing emotional support. This is an opportunity for patients to highlight things that are meaningful for them and have people respond and communicate about them specifically”).

Clinicians thought that people with first episode psychosis will be able to benefit from this program, as they are mostly young and accustomed to this kind of medium. They suggested that people with cognitive impairment who may not naturally use Smartphones or computers, or who may not be able to type will not benefit from this program. Another identified group who might not benefit from this program included people who have a strong net of social support.

Clinicians recommended providing listeners with information about schizophrenia, how to provide support while refraining from providing reinforcement for false beliefs, and how to avoid escalating the situation if they feel misinterpreted. Finally, some clinicians reported the
Beginning the chat on the 7Cups platform

Choosing a listener to chat with

Listener page (information that appears when clicking on a listener’s picture)

Fig. 1. Main screenshots relevant for user/listener interaction.
2.2. Training of listeners

Based on clinicians’ feedback, a computerized training course was developed to provide listeners with relevant information for supporting people with schizophrenia-spectrum disorders. The specialized training made use of features present in the 7Cups training modules, consisting of text, video, and quiz components. The lead author directed the development of this training in collaboration with two psychiatrists (JK, MB) and a clinical psychologist (KC) who are experienced in treating and directing treatment programs for people with schizophrenia-spectrum disorders.

This training included four lessons: (1) “Understanding schizophrenia” — explaining the illness, symptoms, prevalence, and course; (2) “Treatment” — providing details regarding main treatment options, and accessible resources (e.g., National Alliance on Mental Illness line); (3) common misconceptions regarding schizophrenia and psychosis (e.g., You can “catch” psychosis from someone else); and (4) “guidelines for the supporter” — main ways listeners can help support the recovery of those who suffer from schizophrenia (e.g., “supporting without providing reinforcement of false beliefs, encouraging socializing with their family and others”).

A survey was created to evaluate the effectiveness of the program at the end of the training. The survey measured participants’ knowledge of schizophrenia using 6 items (see Appendix A) adapted from National Alliance on Mental Illness (NAMI website, 2015) and Compton et al. (2007) knowledge tests. The survey also measured confidence in the understanding of how to support people with schizophrenia and satisfaction from the computerized training using a 7 items Likert scale ranging from 1 (“not at all”) to 7 (“very”).

A baseline assessment of knowledge and confidence was created by asking 184 randomly picked listeners from 7Cups general list to complete knowledge and confidence items prior to the beginning of the training program. The study criterion for these listeners was at least 2 months experience of volunteering on 7Cups to ensure that only listeners who had some time to get acquainted with the 7Cups program would be engaged. These listeners were also asked to complete the training itself and to conduct the post-training survey, presented at the end of training. The training program and post training survey then became available to all listeners on the 7Cups website. Listeners did not have to complete the survey in order to complete the training.

Statistical analyses were based on two sets of comparisons. One set included the listeners that completed both the pre- and post-training surveys and was analyzed based on paired samples t-tests. While the comparisons based on this sample relate to the change in people’s knowledge and confidence throughout the training program, these changes may be attributed to the fact that these participants saw the questions prior to the training. Therefore, a second analysis was performed by comparing between the listeners’ pre-training results as a “baseline” and post-training results of a group of listeners who met the same criterion of 2 months experience on 7Cups platform, completed the training program, but was not exposed to the survey prior to the training. This analysis was based on t-test for two independent samples.

2.2.2.1. Results. Fifteen listeners out of 36 who completed the survey prior to the training also completed the post survey. Another group of 132 listeners completing only the post-training evaluation were also included in the analyses. Listeners were mostly female (82.7%) and between the age of 18 and 25 (81.0%). In listeners completing both the pre-and post-training questions, knowledge scores increased significantly with large effect sizes (Cohen’s d = 1.08, 1.14; see Table 3 for complete pre- post- training analysis). Listeners without exposure to the pre-training questionnaires, had a significantly higher knowledge and confidence scores in comparison to baseline with moderate effect sizes (Cohen’s d = 0.38, 0.71). Listeners also reported high program satisfaction (Means of 5.48 or above).

2.3. Stage II: patients’ input

The high number of listeners who took part in the training described in stage I (2.2.2) provided flexibility in choosing eligible listeners who would be part of SUPPORT. Following a discussion between the lead author and 7Cups community manager (HC), it was decided to enroll listeners who had met a certain criterion based on their review scores history (see overview of 7Cups program). The criterion was an average reviews score of 4.5 points or above based on at least 20 different reviews provided by 7Cups users. Eighty four trained listeners met this criterion and were included in the listener’s group that appeared available for the selected patients.

2.3.1. Procedure

Patients with a clinical diagnosis of schizophrenia, schizoaffective disorder, or psychotic disorder not otherwise specified (NOS) were recruited from the Zucker Hillside Hospital outpatient clinics to participate each in a 30 minute examination of the online program that

| Item | Neutral | Agree | Strongly agree |
|------|---------|-------|----------------|
| "Patients will recognize the value of SUPPORT." | 4 (66.7%) | 2 (33.3%) |
| "7Cups can be useful in helping patients go through tough times between therapists/counseling meetings." | 2 (33.3%) | 4 (66.7%) |
| "7Cups might be useful in helping patients feel better." | 3 (50%) | 3 (50%) |
| "I believe the benefits of using SUPPORT will outweigh potential drawbacks for the relevant population." | 2 (33.3%) | 4 (66.7%) |
| "SUPPORT might help these patients stay engaged in therapeutic activities." | 5 (83.3%) | 1 (16.7%) |
| "The use of the SUPPORT might improve patient’s outcomes." | 4 (66.7%) | 2 (33.3%) |
included entering the website and conducting an online chat with a listener. First, participants completed a demographic questionnaire. Second, they were presented with a page describing how to use the online platform. Participants were asked to chat with a listener after independently accessing the program through a specialized web page (see Fig. 2), which would then limit the available listeners to those who completed the training program and met study criteria. At the end of the chat, participants were administered a questionnaire with items adopted from previous studies containing statements that include the program usability, usefulness, intentions to use and recommend (Casaló et al., 2008; Lund, 2001; Zeithaml et al., 1996), and attitudes towards the listener (Baumel, 2015). Open-ended questions queried participants about additional aspects including general program feedback and in what ways, if any, it can complement ongoing treatment. All of these steps were in the presence of the study’s lead author which was not part of the clinical staff. Participants received a $30 Amazon gift card compensation for their participation.

Data analysis included descriptive statistics of the multiple-choice questions, and an inductive thematic analysis of the answers to open ended questions regarding general feedback and the ways this program may complement treatment. The later was based on the six-phase method suggested by Braun and Clarke (2006) which includes: familiarization with data, generation of initial codes, searching for themes among codes, reviewing themes, defining and naming themes, and producing the final report.

2.3.2. Results

Four study participants were diagnosed with schizophrenia, 4 with schizoaffective disorder and 2 with psychotic disorder NOS. Participants’ ages ranged between 19 and 42 (M = 28.25, SD = 8.31), 60% were men, 60% were African-American, 20% were Caucasian, and 20% were Hispanic. Two participants (20%) had completed high school, and 8 (80%) had some sort of post high school education (e.g., some years in college).

All participants were able to independently enter the website and connect with listeners based on the printed instructions. All participants rated the emotional support program as usable and helpful, and 90% indicated they liked using the program (see Table 4). Attitudes towards the listeners were generally positive, with 85% of these responses being either “agree” or “strongly agree”. Finally, although all participants indicated that they would use and recommend 7Cups to people who suffer from schizophrenia-spectrum disorders, 4 (40%) were not positive about referring friends to use it, while most of them (3/4) openly stated that they did not wish to involve friends, as they would like to avoid explaining why they use the platform and to accidently expose their illness. 66.7% of participants indicated that they would like to join 7Cups as listeners when they feel better.

2.3.2.1. Thematic analysis. Overall, comments given by nine participants were positive (“I like that they are here to listen”); “I like the fact that

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**Table 3**

Key items scores by pre- and post-training groups, and program satisfaction ratings.

| Item                                                                 | Differences between independent samples | Paired samples differences (n = 15) |
|----------------------------------------------------------------------|----------------------------------------|------------------------------------|
|                                                                      | Baseline (n = 36)                      | Post training (n = 132)             |
| Knowledges test (grade 0–6)                                         | 3.44 (1.38)                            | 3.96 (1.38)                        |
|                                                                      | −2.00 .024                             | .38                                |
| Confidence                                                          | 3.56 (1.87)                            | 4.77 (1.52)                        |
| How much do you think you currently understand how to support people with a schizophrenia-spectrum disorder? | −4.01 <.001                            | .71                                |
| Program satisfaction                                               | 5.48 (1.40)                            | 5.72 (1.38)                        |
| How useful were the topics and areas covered in the training?       | −6.00 (1.13)                           | −9.16 (1.16)                       |
| Were the topics covered relevant to your needs?                     | −5.72 a (1.37)                         | −5.93 (1.37)                       |
| How would you describe your overall satisfaction from this training?| −5.56 a (1.37)                         | −5.73 (1.03)                       |

* These results are based on 129–130 participants answering these questions.

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Fig. 2. The landing page for people with schizophrenia-spectrum disorders.
it was more personal than internet and computers are nowadays because you chat with a person that is replying to you") and all participants provided responses indicating that easily available emotional support could complement the treatment they currently receive. One participant provided a neutral comment relating to the difficulties of connecting to a stranger ("Talking to a complete stranger. It was kind of ok, because she wasn’t making herself seem like a threat or asking too personal Qs").

One theme described by eight participants related to the benefit of being able to find an outlet and receive an immediate response in a moment of need ("Because life happens and you are stressed out at the moment you can’t talk to your counselor because it’s on a scheduled appointment basis"). Another theme described by seven participants related to answering a need to socialize and extend the support they received ("Isolating is a big thing for me, not good for my disorder. Having someone … can be very helpful to me and other people."); "I would use it because now with my disability my friends are married have kids, I’m looking for people to communicate with and it can be helpful in socializing").

3. Discussion

The input gathered from clinicians and patients revealed an overall agreement around the notion that a volunteer-based online program could be beneficial by providing an additional outlet, emotional support and an avenue of socialization for people with schizophrenia. The recognized need for additional support seems to reinforce the notion that internet-based interventions for people with psychosis-related conditions could be helpful when designed to supplement, rather than replace ongoing treatment options (Álvarez-Jiménez et al., 2012).

The fact that some of the participants’ preference was not to refer friends to use this kind of program in order to avoid accidently exposing their illness underscores the stigma and social price that is associated with schizophrenia (Dickerson et al., 2002; González-Torres et al., 2007). This may also provide reasons for favoring this kind of platform, as people may stay anonymous while being able to socialize with others in an environment that may be perceived safer and less judgmental than other settings (Baumel, 2015; Gleeson et al., 2014).

Patients’ positive attitudes towards volunteering on 7Cups as listeners and their answers relating to the wish to communicate with others in the community may also imply that an online volunteer-based support program could benefit people with schizophrenia by providing them with a cyber community. Indeed, online peer support groups and peer-based social networking has already been shown to be engaging and acceptable by people with first episode psychosis (Álvarez-Jiménez et al., 2013). In future research, we aim to examine this notion by exploring cyber community features within 7Cups such as enabling members to communicate with each other, and investigating how these features’ utilization is correlated with clinical outcomes.

3.1. Listeners’ additional training

Overall, the study’s findings support the development of additional computerized training programs as a feasible approach to address volunteers’ knowledge gap in order to prepare them to support people with mental illnesses. In addition, clinicians’ recommendation to guide the volunteers on how to react to certain situations (e.g., how to respond to a person with thought disorders) implies that this kind of program will benefit from establishing a communication channel between volunteers and clinicians that would enable the former to ask for clarifications in times of need. This communication channel can be enabled through the program’s email service, which would notify a designated professional when a question is placed.

3.2. Conclusions

This work is based on previous studies that provided details on the development process of eHealth programs in order to inform administrative staff, developers and researchers in the field (Álvarez-Jiménez et al., 2013; Ben-Zeev et al., 2013; Fjeldsoe et al., 2012). It also presents a feasible and cost effective strategy to develop programs by harnessing available online resources which may propel the uptake of eHealth products.

Table 4
Participant usability, usefulness, intention to use and recommend, and attitudes towards the listeners ratings (n = 10).

|                      | Strongly disagree | Disagree | Neutral | Agree | Strongly agree |
|----------------------|-------------------|----------|---------|-------|----------------|
| **Usability**        |                   |          |         |       |                |
| I found the program accessible and easy to use. | 0 | 0 | 0 | 3 | 7 | (30%) (70%) |
| **Usefulness**       |                   |          |         |       |                |
| I liked to use this service. | 0 | 1 | 0 | 6 | 3 | (10%) (60%) (30%) |
| This kind of support can be helpful for me | 0 | 0 | 0 | 5 | 5 | (50%) (50%) |
| I can see how in a certain amount of time after chatting with listeners, people can feel better. | 0 | 0 | 0 | 4 | 6 | (40%) (60%) |
| **Intention to use and recommend** | | | | | |
| I would recommend this program to people who suffer from schizophrenia spectrum disorders. | 0 | 0 | 0 | 6 | 4 | (60%) (40%) |
| I would recommend on using 7 Cups of Tea to people who suffer from mental health difficulties. | 0 | 0 | 1 | 4 | 5 | (10%) (40%) (50%) |
| I would recommend friends on using 7 Cups of Tea | 0 | 2 | 2 | 3 | 3 | (20%) (30%) (30%) |
| I would probably use 7 Cups of Tea in the future if needed. | 0 | 0 | 2 | 4 | 4 | (20%) (40%) (40%) |
| When I will feel better, I would like to join 7 Cups of Tea as a listener. | 1 | 1 | 1 | 3 | 3 | (11.1%) (11.1%) (33.3%) (33.3%) |
| **Attitudes towards the listeners** | | | | | |
| Listeners can do a good job in supporting people who suffer from schizophrenia. | 0 | 0 | 1 | 6 | 3 | (10%) (60%) (30%) |
| I believe these listeners can help people who suffer from mental health difficulties. | 0 | 0 | 2 | 4 | 4 | (20%) (40%) (40%) |

*One participant did not answer this question. The percentages are calculated based on the 9 participants who answered the question.*
Modifications made to the program based on the described development process include the incorporation of additional computerized listeners’ training, revised criterion for listeners based on their past performance with users, a specialized webpage presenting only eligible performance with users, a specialized webpage presenting only eligible ment process include the incorporation of additional computerized lis-

5. People with schizophrenia benefit most from:
   a. Being put into a hospital for years
   b. Having fun or exercising
   c. Support from family/friends and low stress
   d. Vitamins, minerals, or herbs
   e. I don’t know

6. 19-year-old begins to hear voices and act paranoid several months after graduating from high school. The most likely cause of his symptoms is:
   a. Drinking alcohol
   b. Genetic tendency toward developing an illness
   c. Graduating high school
   d. Personality weakness
   e. Puberty and adolescence
   f. I don’t know

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Appendix A. Knowledge test

1. Schizophrenia is characterized by:
   a. Hallucinations
   b. Disordered thinking
   c. Emotional unresponsiveness
   d. All of the above
   e. I don’t know

2. Medicines that are used for hearing voices are called:
   a. Antibiotics
   b. Anti-depressants
   c. Anti-psychotics
   d. Sedatives
   e. Tranquilizers
   f. I don’t know

3. A person strongly believes that the FBI has put a computer chip in his/her body. This symptom is called a:
   a. Daydream
   b. Delusion
   c. Hallucination
   d. Phobia
   e. Worry
   f. I don’t know

4. Most people who have schizophrenia need to be in some sort of treatment for:
   a. Days
   b. Weeks
   c. Months
   d. Years
   e. Not at all
   f. I don’t know

5. People with schizophrenia benefit most from:
   a. Being put into a hospital for years
   b. Having fun or exercising
   c. Support from family/friends and low stress
   d. Vitamins, minerals, or herbs
   e. I don’t know
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