Depression support group: participants' evaluation and perceived effects

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Summary

Objective: *To study the perceived effects and satisfaction by participants of depression support groups.*
Design: *Analysis of written responses to a questionnaire with nineteen items under three categories.*
Subjects: *Participants who had joined the 'Dance with Depression Support Group' within the year 2002-2004.*
Main outcome measures: *Participants opinion on the group structure, group process and their perceived effects on their mood, cognition, self esteem, and interpersonal relationships.*
Results: *Participants were satisfied with the location, time and duration of the group. Groups of 6-8 members were regarded as appropriate. Perceived effects included better control of emotions, beneficial changes in cognition, increase in self esteem, improved interpersonal relationships and decreased suicidal ideation. No particular ill effects were reported.*

Conclusion: *Depression support groups appeared to be beneficial to patients with depression. Objective measurements using validated tools are required to determine the magnitude and duration of the effects perceived by the participants.*

Keywords: *Depression, support group, participants evaluation, perceived effects*

摘要

目的：研究曾參與抑鬱症支援小組人仕在活動後所感到的效果和滿意程度。
設計：對歸納為三類的19項填寫式問卷調查回應作分析。
對象：於2002-2004年期間曾參加「與抑鬱症共舞」支援小組的人仕。
測量內容：參與者對下列的意見：小組的組成，活動過程，以及他們對自己情緒，認知能力，自信及人際關係方面所感受到的影響。
結果：參加者均滿意舉辦該活動的地點，時間及時間長短。每組8至10人被視為恰當的。他們所感受到的成效包括更佳的情緒控制，認知能力和自信心得到提高，改善人際關係及減少自殺念頭。並無特別不良影響的報告。
結論：看來抑鬱症支援小組的活動是對抑鬱症患者有益的。但需要以認可方法客觀地量度和確定參與者所感受到成效的重要性及持續性。

主要詞彙：抑鬱症，支援小組，參與者評估，感受效果

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* *The Dance with Depression Support Group is a charitable organization that organizes support groups for patients with depression. Further details can be obtained via the website: http://www.dancewdepressionsg.org*

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Introduction

Despite medical and psychological treatments, the prognosis for moderate to severe depression is still poor. One study showed a 67% recurrence rate at 30 months

follow up[1] and another study showed only 12% recovery rate at 25 years follow up.[2] Depressed patients have little social support. Interpersonal difficulties and deficits have been regarded as causes as well as consequences of depression.[3,4] While patients with other illnesses like hypertension or diabetes mellitus are willing to discuss their illnesses openly, this is not true with patients who have psychiatric disorders for fear of stigmatization and discrimination, which in turn would cause additional stress to them and their families.[5,6] It is hoped that within a support group, participants would experience a sense of belonging and feel being understood and accepted when they share their experience with those who have the same experience and at the same time may learn alternative ways of relating and coping in everyday life.[7-9] They would also learn that they are not alone in their struggles. With similar intentions, the 'Dance with Depression Support Group'* has been holding support groups for patients with mood disorder since 2002.

With regards to the effectiveness of depression support groups, controversial results were obtained from different studies from the literature. Favourable results were described in studies on depressed cancer patients,[10] postnatal distressed women,[11] depressed patients,[12,13] and alcoholics and substance abusers.[14] However, other studies such as studies on emotional disorder[15] and postnatal depression[16] failed to show beneficial effects from support groups. The availability of social support in their own living environment, the presence of professionals as facilitators, the level of involvement within the group, the provision of useful information with regard to their illness were all implicated or suggested as factors affecting the effectiveness of the groups. Very little is reported about depression support groups in Hong Kong. Therefore, through this study, more about the expected benefits by depressed patients in our community may be known.

The group structure

Each group was a close group consisting of 4-10 participants. There were two facilitators in each group. All facilitators have counselling and group experience during their training and more than half of the facilitators have experience in organizing, facilitating and leading groups. The groups met weekly for two hours and lasted for six months with possibility of an extension of another three months depending on the participants' preference.

The recruitment process

Participants were recruited by referrals from psychiatrists, medical practitioners, counsellors or social workers. There were pre-enrollment interviews to assess whether the candidates were suitable to join the group. Acceptance criteria included patients who were 18-50 years old suffering from major depression or dysthymia and had received secondary level education. They should also be receiving either medical treatment and/or counselling service. Patients with psychotic features and high suicidal risks would not be accepted into the group.

Group activities

Group members were encouraged to share their experiences and give feedback to other members. Facilitators would monitor the gatherings and provide feedback when appropriate. There were regular psycho-education classes delivered by psychiatrists and depending on what issues were brought up during the gatherings, facilitators might use different techniques at the meetings. Debriefing sessions were held after each meeting for the facilitators to report on the process, exchange views, share experience and to receive inputs from the resource persons.

Methodology

Participants' feedback was obtained by use of a questionnaire with 19 items under three categories. The questionnaire was developed by two of the investigators on three main aspects: i) the time, duration and location of the gatherings; ii) the recruitment process and iii) perceived effects experienced by the participants. The questionnaire was circulated to all investigators and facilitators for comments and alterations made to minimize ambiguity. Apart from "yes/no" answers, there were open-ended questions to ask for subjective changes after joining the group. Participants were also asked about their opinion on the groups and the group process. Themes were identified and agreed upon by two of the investigators. When responses given did not correspond to the correct category, they were re-categorized by the investigators and agreed upon for analysis.

Results and discussions

Thirty-seven questionnaires were sent to members who joined the groups after making telephone contact and the groups were terminated at the end of the period 2002-2004. Twenty two questionnaires were returned giving a response rate of 59.5%.

Demographic data:

The majority of those who responded, (70%) were females. However, about half (54.5%) of the respondents did not disclose their gender. Only 2 respondents (9%) disclosed their occupation. Most of the participants did not wish to disclose their identity.

Table 1: Demographic data of participants (N=22)

		Number	Percentage
Gender:	F	7	70% (N=10)
	M	3	30 (N=10)
	No response	12	
Occupation:		2 (one jobless, one kindergarten teacher)	9%
	No response	20	91
Age:	20-30 years	2	9%
	31-40	9	41
	41-50	7	32
	>50	4	18

1) General comments on the venue, time and duration of the gatherings:

All agreed that weekly gathering each lasting for two hours were appropriate. Most responded that the location in Central (81.8%), starting at 7pm (86.4%), and ending at 9pm (86.4%), and at duration of six months for the whole programme were suitable. Three participants in one group of ten members and one participant from another group of seven responded that the group size was too big. One participant from a group of four said that the group size was too small. All other participants (63.6%) felt the group size was appropriate. The findings on group size concurred with opinions of various authors on group therapy.[7-9]

Table 2: Comments on the venue, time and duration of gatherings (N=22)

	Appropriate No (%)	Inappropriate No (%)	No response No (%)
Location:	18 (82%)	4 (18%)	0%
Starting time:	19 (86.4)	3 (13.6)	0
Ending time:	19 (86.4)	1 (too early) (4.5) 1 (too late) (4.5)	1 (4.5)
Duration:			
Each session (2 hours)	22 (100)	0	0
Total (6 months)	19 (86.4)	1 (too short) (4.5) 1 (too long) (4.5)	1 (4.5)
Frequency of gathering: (Weekly)	22 (100)	0	0
Group size:	14 (63.6)	4 (too large) (18) 1 (too small) (4.5)	3 (13.6)

2) Comments on the selection process:

Both positive and negative feelings were reported on the selection process. Some felt terrified, anxious, stressed, surprised, tensed and uncomfortable because there were too many interviewers and the atmosphere was too serious. Here below are some of the comments.

'**很像見工面試，格局太拘束**'
"The interview setting was too formal; it's just like a job interview ....." (11)

'**感受嚴肅，因太多人面見**'
"The atmosphere was tense because there were too many people in the room" (7)

Some felt hopeful, were comfortable and happy because the interviewers were friendly and professional.

'.....**很認真地揀選參加者，令我相信**.....'
".....with the careful and serious selection process, I am confident ....." (20)

'.....**甄選者很友善，可安心把**.....'
"The interviewers were friendly, I felt comfortable to ....." (3)

Information about the group was regarded as sufficient by 54.5% and regarded as insufficient by 27.3% of participants. 18.2% did not respond. Participants would like to know more about other group members before joining the group. Some of the comments are as follows.

'.....其他組員的資料欠奉，不知能否適應.....'
"..... didn't obtain any information about the other group members, not sure whether I can adjust ....." (2)

It appeared that the presence of professionals within the group would give participants a sense of trust. On the other hand, the large number of interviewers would cause anxiety. Some participants showed concern about other members of the group and it would be a good idea to let members have a trial period first.

3) Feedbacks on the gatherings:

a) Sharing of feelings

Most (81%) felt comfortable to share their feelings. Some felt that the time for sharing was too short. This might show that depressed patients yearned for an appropriate place for people to listen to them and felt comfortable just by sharing.

'有好幾次很舒服，但時間不足'
"I felt comfortable but insufficient time ....." (21)

Some (9.1%) found it difficult to express their feelings in a group setting

'因每人的背景、文化、生活習慣不一樣，有時會猶豫說出自己的經歷 .....'
"Because of differences in background, culture and living habits amongst members, sometimes I hesitated to share my experiences ....." (6)

b) Mutual support within the group

The majority (86.4%) felt that they received support from the group, whilst 9.1% did not receive any support. Amongst those who received support, 55% were from the group members, 55% from the facilitators and 30% of members received support even after the gathering. The participants valued emotional support from others.

'組員、組長們都很支援有問題的組員'
"The group members and facilitators were very supportive to members having difficulties." (16)

'各組員會分析提出一些合適的建議.....'
"Group members helped analyzing and giving appropriate suggestions ....." (14)

'講述自己類似情況 .....，覺得自己並不孤單 .....'
"I shared my own condition ....., feel I am not isolated." (22)

Most (77.3%) of the members felt that they had supported others. For those who did not give support, gender difference may be one of the factors.

'我是男性，較需要幫助的是女性'
"I am a male and those in need were females." (3)

Facilitators also played an important role in giving support. There were positive and negative comments. Sometimes, there might be over expectation from facilitators, such as expecting support even after the gatherings.

"xx (facilitator) and yy (facilitator) gave us a lot of support ....." (5)

'如有緊急需要精神支援，也沒有任何人士可以聯絡....'
"psychological support was not obtained during acute need." (21)

Beneficial effect in social support is bi-directional.[17] It was also shown in our participants. Therefore, it is important that participants in the support group are able to receive and at the same time to give support to others.

4) Changes after joining the group:

All except one felt that there were changes in themselves in one or more of the following areas after joining the group.

Table 3: Chance to share, obtain and provide support (N=22)

	Yes No (%)	No / No response No (%)
Sharing	19 (86.4%)	3 (13.6%)
Obtained support	17 (77.3)	5 (22.7)
Provided support	14 (63.6)	8 (36.4)

i) Mood: 62% reported changes while 33% reported no change in mood.
Changes included more awareness and acceptance of their emotions, more stable mood, and more in control of emotions.

'**多留意自己的情緒轉變**'
"..... pay more attention to own emotional changes ....." (9)
"..... have better control of emotions ....." (4)

'**平和了，沒有惶恐心慌感覺**'
"..... more peaceful, no more fear and panics ....." (10)

ii) Cognitive/behaviour: 81% reported changes while 14% reported no change.
Changes included more positive thinking, more accepting and more open in behaviour.

'**調適自我心態、觀點**'
"..... adjust my views and attitude .... (15)

'**做人是無常的，學習怎樣去面對**'
"Life is unpredictable, and I will learn how to face it ....." (16)

iii) Physical health: Fourteen (63.6%) reported subjective improvement of their physical health.
These include better sleep, less pains and aches, and "feeling healthy".

'.....**不再頭痛，甚少再胃痛** .....'
"..... don't have headache, seldom have stomach ache...." (5)

'**睡眠質素有改善**'
"Quality of sleep improved ....." (20)

iv) Interpersonal relationship: Fifteen (68%) reported improvement of their interpersonal relationships.
Improvements included being more relaxed, more initiatives, more open with people, and more concern about others' feelings and needs.

'**敢與陌生人兩眼正視及放鬆交談**.....'
"have courage to look at strangers and talk freely ....." (5)
'**學懂應體諒和關心別人**'
"learn to be considerate and care for others ....." (16)

'**由於情緒、健康及自我形象穩定了，人際交往的能力相應地提升了** ....."
"because of more stable mood, health and self esteem, interpersonal skills are improved ....." (2)

v) Self image: Thirteen (59%) reported improvements in perception of self which included more self confidence and more self acceptance.

'**重拾自信，自我形像提升了**.....'
"more self confidence" (2)(3)(9)

'**明白接受自己的過去** ....."
"I understand and accept my past ....." (21)

vi) Suicidal tendency: None attempted suicide. Thirteen (59%) did not have suicidal ideation. Five (22.7%) reported that suicidal ideation had lessened and were able to seek help even if there was ideation.

'**當盟死念時，便抓人說，要快** ....."
"Even if there is ideation, I would find some body to talk to ....." (11)

Only one reported no change after joining the group. The rest of the participants described changes in different areas and different degrees of changes. Most important of all, none reported negative changes in themselves. This concurs with the results in another study on depressed cancer patients, which showed that social support intervention resulted in fewer psychological symptoms, reduced maladaptive interpersonal sensitivity and anxiety.[10]

Table 4: Perceived changes after joining the group

	Changes	No change / no response
	No. (%)	No. (%)
Mood (N=22)	13 (59%)	9 (41%)
Cognition/ behaviour (N=22)	17 (77.3)	5 (22.7)
Interpersonal relationship (N=22)	12 (54.5)	10 (45.5)
Self esteem (N=22)	11 (50)	11 (50)
Suicidal ideation (Lessened)	5 (22.7)	4 (18.2)
Reported no suicidal ideation		13 (59)

5) What participants like most in the group: whether meeting expectations or not:

About 63.6% of participants reported that the group met their expectations and 13.6% reported that their expectations were partially met and 18% reported that their expectations were not met.

Things that the participants like most were: the safe and friendly atmosphere; mutual support, acceptance and encouragement from the group; ability to share thoughts, feelings and experiences freely; and networking with new friends with the same illness.

'**很安全，沒歧視**.....'
"very safe, no discrimination ....." (11)
"can share thoughts easily ....." (12)

'**在小組認識現在的好朋友**.....'
"make good friends with group members ....." (17)

'**有一個** gathering **的地方，知道在那裏能找** support'
"a gathering place where I can get support ....." (22)

'**無私關愛的心**'
"Unconditional care and love." (5)

'**大家彼此接納，互相鼓勵支持**'
"Mutual acceptance, encouragement and support." (2)

In summary, the group was able to provide a safe and supportive environment for patients with depression and that is what they needed most. No details were given for those who reported that the group had not met their expectations.

6) What the participants dislike most:

One commented that facilitators were too silent, not leading the group well and not providing sufficient support. With regard to the process, two commented that the gatherings were too "free flow" without a definite focus during each gathering. Members also disliked arguments and gossips within the group and felt pressured and guilty if they did not respond to other member's questions or failed to turn up. Some reported that the facilitators were not able to give support and guidance after the meeting. It may be necessary to emphasize to future participants that additional service may not be possible after the group meeting. Other unmet expectation included too much emphasis on drugs by psychiatrists who gave talks on psycho-education. One particular member self-blamed and self-criticized for the group not meeting her expectation.

The feedback showed that facilitators should be skilled to handle arguments and gossip amongst members and make use of these opportunities to help participants to face such issues both within the group and in real life. Self-blame is also common amongst depressed patients and similarly it should be regarded as an opportunity to help them change cognition and improve their self esteem.

Limitations

There were different confounding factors affecting the well being of the participants. The responses were subjective responses and there were no objective assessments. Concurrent medication and counselling services were not taken into account and there was no control group for comparison. Non-responders were not accounted for. There was time lapse between the termination of the group and giving feedback so that there may be recall bias. The changes were not followed up for the duration and therefore it is not known how long the reported effects would last. Also the number of participants may be too small to draw any reliable conclusions. In addition, facilitators may be different for each group although there is a consensus as to how the groups should be run and there was debriefing after each meeting to give mutual support and suggestions for future sessions. Future studies are required to obtain more evidence on the effectiveness of these support groups. Baseline assessment should be done using

Key messages

1. Interpersonal difficulties and deficits are regarded as causes as well as consequences of depression.
2. Support groups exclusively for patients with depression offer a safe environment for patients with depression to share and learn coping strategies.
3. Subjective experience of participants of local depression support groups showed beneficial effects.
4. Depression support groups may be regarded as a supplement to medical/psychological treatment.

validated scales before joining the group and further assessments including feedback should be obtained immediately at termination and at set regular intervals of, say, at 6 months, one year, two years etc. in order to assess the duration of the effects.

Conclusion

Perceived benefits by the participants are encouraging although these may not be generalized for all depressed patients particularly elderly ones. Most participants reported beneficial effects on mood, cognition, interpersonal relationship, and self esteem. Depression support groups could therefore, be regarded as a supplement to medication for clients with depression.

It appeared that the time (7-9 pm) and duration (two hours weekly for six months) of the gatherings are appropriate and welcomed by members. The appropriate size of the group should be 6-8 members. The selection process should include fewer interviewers so as to be less threatening. It is useful to allow a trial period so that participants can withdraw if they feel that the group is not suitable for them. The group did fulfill the original goal of providing a safe environment for sharing, obtaining mutual support and giving the participants a sense of belonging. Facilitators and resource persons are all volunteer workers. This may not be cost effective from a public health point of view if all workers are paid staff. However it is a good idea to solicit help from retired professionals such as medical practitioners, social workers, counsellors and nursing staff who are willing to contribute their time and expertise for voluntary work in this area. More prospective studies are needed to further prove the effectiveness as well as the extent of the effects. Recent studies also showed benefit in organizing Internet support groups for depression.[18-20] It is worthwhile to compare the effectiveness of these groups with face-to-face support groups in our local community.

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「與抑鬱共舞小組」問卷

「與抑鬱共舞支援小組」現正進行一項問卷調查，希望聽取各組員對小組的意見。您的意見對小組未來的方向與發展，有很大的幫助。希望您能抽出寶貴的時間，填寫這份問卷。

這份調查問卷以不記名的方式進行，並且絕對保密，調查完畢後，所有問卷將會全部銷毀。

姓別 ：男 / 女

年齡 ：20-30 □　31-40 □　41-50 □　〉50 □

職業 ：(optional)

(一). 小組聚會意見

1. 舉行小組聚會的地點：　適合／不適合
   如不適合，請說明原因(　　)
2. 舉行小組聚會的環境：　舒服／不舒服
   如感覺不舒服，請建議如何改善(　　)
3. 每次開組的時間（晚上７時）　太早／適合／太遲
4. 每次完結的時間（晚上九時）　太早／適合／太遲
5. 每次聚會的時限（兩小時）　太短／適合／太長
6. 聚會頻密的程度（每星期一次）太頻密／適合／太疏
7. 每組總共的時限（六個月）　太短／適合／太長
8. 小組的人數適合嗎（請填上您參加的組別及的人數）：
   組別 （　　）人數(　　)
   適合／不適合
   如不適合，請說明原因(　　)
   如有其他意見，請提供：(　　)

(二). 甄選過程意見

1. 請憶述甄選過程的感受：(　　)
2. 甄選後，您認為已經掌握到小組的概況（或得到小組的資料）嗎？　足夠／不足夠
   如不足夠，請說明那一方面足夠 （　　）
3. 其他意見 （　　）

(三). 聚會的過程

1. 在小組裡，我（能否）有沒有
   1.1 抒發感受　有／沒有
   如果有，請說出次數　很多／幾多／好幾次／一兩次
   請說出感受　很舒服／幾舒服／普通／不太舒服／很不舒服
   如有意見可提出：(　　)
   如果沒有，請說出原因：(　　)
   組長問題：(　　)
   組員問題：(　　)
   自己問題：(　　)
   其他：(　　)
   1.2 在小組裡得到支援　有／沒有
   如果有，請說出次數　很多／幾多／好幾次/一兩次
   請說出情況　組員支援／組長支援／聚會後支援
   其他：(　　)
   如果沒有，請說出原因：(　　)
   組長問題：(　　)
   組員問題：(　　)
   自己問題：(　　)
   其他：(　　)
   1.3 您覺得自己有否幫助別人　有／沒有
   如果有，請說出次數　很多／幾多／好幾次／一兩次
   如果沒有，請說出原因
   組長問題：(　　)
   組員問題：(　　)
   自己問題：(　　)
   其他：(　　)
2. 您參加小組後有沒有改變　有／沒有
   如果有，請說出那些方面有改變 （　　）
   認知行為：（　　）
   情緒心理：（　　）
   身體健康：（　　）
   人際交往：（　　）
   自我形象：（　　）
   自殺傾向：（　　）
   其他：（　　）
3. 您最喜歡小組的地方是：（　　）
4. 您最不喜歡小組的地方是：（　　）
5. 您認為小組在那方面可作出改善：
6. 小組的活動能達到您的期望嗎？
   達到／不能達到
   如不能達到，請說出那些方面未達到：(　　)