Exploring the impact of training on the experience of Australian support group leaders: current practices and implications for research

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Abstract

Background Existing literature suggests that the effectiveness of a support group is linked to the qualifications, skills and experience of the group leader. Yet, little research has been conducted into the experiences of trained vs. untrained support group leaders of chronic-illness support groups. The current study aimed to compare the experience of leaders, trained vs. untrained in group facilitation, in terms of challenges, rewards and psychological wellbeing.

Methods A total of 358 Australian leaders of cancer and multiple sclerosis (MS) support groups, recruited through State Cancer Councils and the MS society (response rate of 66%), completed a mailed survey.

Results Compared with untrained leaders, those with training were significantly younger, leading smaller groups and facilitating more groups, more frequently (all $P < 0.05$). Trained leaders were more likely to be female, educated beyond high school, paid to facilitate, a recipient of formal supervision and more experienced (in years) (all $P < 0.01$). Untrained leaders reported more challenges than trained leaders ($P < 0.03$), particularly struggling with being contacted outside of group meetings (52%) and a lack of leadership training (47%). Regardless of level of training, leaders identified a number of unmet support and training needs. Overwhelmingly, leaders found their facilitation role rewarding and the majority reported a high level of psychological wellbeing.

Conclusions Group facilitator training has the potential to reduce the burden of support group leadership. Developing interventions to assist support group leaders will be particularly beneficial for leaders with minimal or no training group facilitation training.

Introduction

Psychosocial support in the form of support groups is a valuable resource for patients diagnosed with chronic illnesses such as cancer and multiple sclerosis (MS). Support groups, also referred to as self-help or peer discussion groups, offer people with common issues the opportunity to meet and share their experiences, knowledge, strengths, fears and emotions without censure, in a safe forum. Benefits of attending a support group include improvements in quality of life,[1] enhanced coping[2] and psychological wellbeing.[3]

There is considerable variation in the literature as to the definition of a support group, with the terms support, self-help and treatment group, often used interchangeably.[4–6] This view is supported by Herron (2005)[7] who notes an absence of agreed definitions on the types of support groups and overlap between types of support groups. Schopler and Galinsky (1983), drawing on the work of Rosenberg (1984),[6] describe support groups on a continuum, with self-help groups at one end of the spectrum and treatment groups at the other.[5] Characteristics that vary and thus define these groups include the basis of leadership and the understanding of participants' roles.[5,6] Self-help or mutual-aid groups tend to be characterized by little or no variation between roles of the participants and the leader, with the common experience linking the group also common to the leader.[5,6] Such commonality of shared experience between leader and members does not usually occur in therapy groups, where there is a clear delineation between leader and the group member, and the expectation of both members and leader is of treatment and possibly cure.[5]

Research suggests support group leaders play a crucial role in determining the success of support groups[8–10] and the experience of group members.[11,12] Yalom (2005)[13] outlines three fundamental roles of a group leader; (i) to create and maintain the group, that is, to recruit and encourage group cohesion; (ii) to build the culture of the group and develop norms and (iii) to activate the here-and-now, that is, to evoke emotion.

Whilst leading a support group can be very rewarding, it can also be a challenging and often emotionally demanding role. Group members may vary in stage and severity of illness, responsiveness to treatment, life expectancy, age, personality and coping skills, thus requiring a leader to co-ordinate and accommodate the members' many different needs and expectations.[14] Group leaders often have a personal history or direct experience with the problem or illness central to the group. They may conduct the support group in a voluntary capacity, or alternatively, are trained health professionals who conduct the group as part of their job. In Australia, there are almost an equal number of professionally-led and volunteer peer-led cancer support groups.[7] Increased longevity has resulted in a greater amount of free time post-retirement.[15] This, coupled with increased success in the treatment to the point of cure, has increased the number of (untrained) volunteers who may choose to become a support group leader. Increasingly, organizations are moving beyond trained health professionals to provide support and education, and adapting programmes so that they may be conducted by volunteer lay leaders.[16]

The effect of group facilitation training on the experience of group leadership is not well understood. While a distinction is often made between professional-led and volunteer-led support groups, with respect to group facilitation training, such categorization may be misleading as group facilitation training is not a major component of many undergraduate or postgraduate health professional degrees.[12] Yet, many health professionals or counsellors trained in individual therapy are expected to facilitate support groups.[17]

Challenges commonly cited by support group leaders include practical difficulties, such as a lack of resources, and poor recognition by medical professionals and health services,[9,18–20] and professional and personal challenges, such as finding the balance between personal and professional life, preventing burnout, maintaining group confidentiality and dealing with

worsening health and death of group members.[20] These issues have been found to be particularly challenging when a leader's personal disease experience closely resembles that of a group member.[20,21]

A number of shortcomings are apparent in the existing literature, including small sample sizes (n = 20–67)[18,20,21] and homogeneous samples.[9,18,19] Importantly, the experience of leaders has mostly been explored indirectly through the experience of cancer support group members.[9,18,19] Understanding support group leadership is essential if effective interventions to enhance support and training of group leaders are to be developed.

The current study aimed to comprehensively investigate the experience of support group leaders by: (i) exploring and documenting leader challenges, rewards and psychological wellbeing within two different disease types, cancer and MS. The leaders of cancer and MS support groups were chosen on the criterion of unpredictable disease exacerbation, potential functional impairment and potential lack of cure of the members. Further, cancer and MS support groups represent some of the best-organized support networks in Australia; and (ii) determining the difference, if any, group facilitation training has on the level of challenges, reward, unmet needs and psychological wellbeing reported by leaders. Because this is a relatively new area of enquiry, a cross-sectional survey design was used to look for indicative associations, which could be further explored in more targeted research.

Method

Participants

A support group leader was broadly defined as an individual who leads support group meetings, and can be trained or untrained, consumer or health professional or both.[7] A support group was regarded as two or more people meeting face-to-face under the guidance of a leader or facilitator to seek support in their experience of either cancer or MS. Eligible participants were those who had previously led, or were currently leading, a support group for adults with MS or cancer and/or their carers. Excluded from participation were leaders not proficient in English, leaders of support groups for children and/or adolescents, and leaders of groups who did not have face-to-face contact. Eligible participants were identified through collaboration with state-based coordinating bodies for cancer and MS support group services across Australia. Additional leaders were identified and invited to participate using a 'snowballing' technique (i.e. inviting participants to nominate other potential participants).

Based on whether leaders identified as having training in group facilitation, the length of time spent on training, the institution where the training was received and any awards, degrees or diplomas received upon completion of the training, participants were categorized into one of two groups: (i) leaders who reported 12 months or more of group facilitation training were considered to have advanced training, vs. (ii) leaders with < 12 months of training were considered to have basic to no training. As not all health professionals are trained in group facilitation (e.g. nurses), an effort was made to be conservative when categorizing participants. In cases where incomplete information was provided on the level, type and length of group facilitation training, no or basic group facilitation training was assumed. As a result of the categorization process, health professionals were common to both groups, although social workers, psychologists and counsellors dominated the advanced trained category. For ease of reading, the 'advanced' and 'basic' trained categories will be referred to broadly as 'trained' and 'untrained' respectively. This is not to negate the leaders who have basic training, but to reflect the fact that the majority of this group (n = 250, 82%) had either none or < 1 week of group facilitation training, with an overall group mean of 1 day. Categorization was conducted by one of the authors (RZ) and a research assistant, and independently checked by a statistician (MC), to ensure reliability.

Procedure

Collaborating bodies provided the names and contact details of leaders to the research team, who telephoned them to introduce the study. Eligible and consenting leaders were sent a study package including the participant information sheet and consent form, the study questionnaire, and a reply paid self-addressed envelope. Non-respondents were contacted by telephone or, if non-contactable, were sent a replacement questionnaire pack. As a result of state preference, a slight variation in the recruitment protocol occurred in two states, where an initial letter was sent from the Cancer Council, which was then followed by telephone contact from the research team as per study protocol. Ethics approval was obtained from the University of Sydney Human Research Ethics Committee and the MS Society.

Measures

Demographic and leadership details were elicited, including leaders' age, gender, marital status, paid employment status, personal experience with cancer/MS, how they became a group facilitator, the structure of their group and their role in the support group.

Challenges, rewards and unmet support and training needs of leaders were assessed using four purpose-designed scales. These subscales were constructed on the basis of results from a previous study,[20] and assessed: practical challenges (24 items), personal and professional challenges (30 items), rewards (seven items) and unmet support/training needs (eight items). Participants responded to items on a five-point Likert scale, ranging from Strongly Disagree (1) to Strongly Agree (5). A 'not applicable' response option was available, as some questions may have not been relevant to all leaders. Higher scores indicate greater degrees of challenges, rewards and unmet needs. The scales were successfully piloted with cancer ($n = 8$) and MS leaders ($n = 8$). In the current study, overall internal consistency of the challenges and rewards subscales was adequate (practical challenges: $\alpha = 0.83$, personal/professional

challenges: $\alpha = 0.91$, rewards: $\alpha = 0.86$). The internal consistency of the unmet needs subscale was not calculated as each item represented an independent area of inquiry.

Stress and burnout was assessed using the Maslach Burnout Inventory-Human Services Survey (MBI-HSS).[22] This survey consists of three subscales, which independently assess Emotional Exhaustion (EE), Depersonalization (DP) and Personal Accomplishment (PA). The MBI-HSS is a widely used scale because of its clinical relevance and sound psychometric properties.[23] Higher levels of EE and DEP, and lower levels of PA indicate higher levels of burnout.

Levels of depression, anxiety and stress were assessed using the Depression, Anxiety and Stress Scale (DASS-21).[24] This scale was used for its relevance to non-clinical samples and robust psychometric properties.[25,26] Higher scores indicate greater levels of anxiety, depression and stress.

Data analysis

Descriptive statistics including the means, standard deviations and percentages were used to describe the sample and leaders' challenges, rewards, needs and psychological wellbeing. As appropriate, independent samples *t*-test or chi-square analyses, were calculated to determine the effect of disease type and group facilitation training on the experience of support group leaders. If Levene's test indicated violation of the homogeneity of variance assumptions, the Welch-Satterthwaite approximation for the case of unequal variance was used. All analyses were conducted using Statistical Package for the Social Sciences (SPSS) v16.0 (SPSS Inc., Chicago, IL, USA).

Results

Demographic and group characteristics

The final sample consisted of 358 support group leaders (cancer $n = 292$, 83%; MS $n = 61$, 17%), corresponding to a response rate of 66%. Comparative analysis of participants and non-participants, using the variables of leader

gender, geographic location and specificity of support group (general vs. specific), found no significant differences between participating and non-participating support group leaders. Of participating leaders, the majority of participants were female ($n = 279$, 79%), born in Australia ($n = 290$, 82%), with many having a personal diagnosis of MS or cancer ($n = 207$, 59%). The majority of participants were categorized as untrained in group facilitation ($n = 313$, 88%).

Trained leaders reported significantly more years (M = 12, SD = 12.1) of leadership experience (mean difference = 6.64 years, 95% CI: 2.66, 10.63) than untrained leaders (M = 6, SD = 6.1). Trained leaders were facilitating more support groups (M = 2, SD = 0.8) than untrained leaders (M = 1, SD = 0.7; Mean difference = 0.4, 95% CI: 0.11, 0.69) and were also conducting smaller sized groups (M = 11, SD = 5.0) than untrained leaders (M = 15, SD = 10.2; mean difference = −4.02, 95% CI: −5.99, −2.05) (see Table 1). Untrained leaders were more likely to have a personal diagnosis of cancer or MS ($n = 197$, 63%), compared with trained leaders ($n = 10$, 25%) and were facilitating the support group in an unpaid, voluntary

capacity ($n = 250$, 80%) compared with trained leaders ($n = 7$, 17%). Of note, were the leaders identified as untrained who were paid to facilitate a support group ($n = 58$, 19%). Untrained leaders were significantly more likely to be facilitating their support group without professional supervision ($n = 258$, 83%) compared with trained leaders ($n = 23$, 57%) (see Table 2).

There were no differences in the number of challenges, rewards or unmet needs or levels of psychological wellbeing reported in the cancer vs. MS leaders; therefore, the samples were combined for all subsequent analyses. Analysis using the categories of health professional (e.g. nurse, psychologist, social worker) and non-health professional, found no significant difference between the two groups on any of the abovementioned measures.

Challenges of support group leadership

On average, support group leaders scored 131 (SD = 22.5), out of a possible score of 275, indicating that, overall, leaders did not experience a high level of challenge in their facilitator role.

Table 1 Support Group Leader and Group demographic information

	Total (n = 353), M (SD)	Trained (n = 40), M (SD)	Untrained (n = 313), M (SD)	t^1	d.f.	P	Mean diff.	95% CI of difference
Age in years	57 (12)	52 (9)	57 (12)	−2.584	342	0.010	−5.28	−9.30, −1.26
Valid, n	344	36	308					
Years as a group leader	6 (7.4)	12 (12.1)	6 (6.1)	3.366	40.6	0.002	6.64	2.66, 10.63
Valid, n	342	39	303					
Years leading current support group	5 (4.2)	4 (3.5)	5 (4.3)	−0.540	335	0.590	−0.39	−1.80, 1.03
Valid, n	337	39	298					
Average number of attendees	14 (9.8)	11 (5.0)	15 (10.2)	−4.046	87.9	<0.001	−4.02	−5.99, −2.05
Valid, n	346	40	306					
No. support groups currently conducted	1(0.7)	2 (0.8)	1(0.7)	2.774	45.2	0.008	0.40	0.11, 0.69
Valid, n	344	40	304					

[1]If Levene's test indicated violation of the homogeneity of variance assumption, the Welch-Satterthwaite approximation for the case of unequal variances was used.

Table 2 Support Group Leader demographic information

	Total sample (n = 353), N (% total)	Trained (n = 40), N (% trained)	Untrained (n = 313), N (% basic)	χ^2 (d.f. = 1)	P
Gender				6.94	0.008
Female	279 (79)	38 (95)	241 (77)		
Male	74 (21)	2 (5)	72 (23)		
Level of education				21.71	<0.001
High school only	123 (35)	2 (5)	121 (38)		
Beyond high school	174 (49)	34 (85)	140 (45)		
Missing data	56 (16)	4 (10)	52 (17)		
Leader diagnosed with cancer/MS				22.04	<0.001
Yes	207 (59)	10 (25)	197 (63)		
No	142 (40)	30 (75)	112 (36)		
Missing data	4 (1)	0 (0)	4 (1)		
Paid to facilitate the support group				74.31	<0.001
Yes	91 (26)	33 (83)	58 (19)		
No	257 (73)	7 (17)	250 (80)		
Missing data	5 (1)	0 (0)	5 (1)		
Has formal group facilitation training				35.02	<0.001
Yes	195 (55)	40 (100)	155 (50)		
No	151 (43)	0	151 (48)		
Missing data	7 (2)	0	7 (2)		
Time spent on group facilitation training	(n = 195) (%)	(n = 40) (%)	(n = 155) (%)		
Less than 1 week	99 (51)	0 (0)	99 (64)		
1 week to 12 months	35 (18)	0 (0)	35 (23)		
More than 12 months	40 (20)	40 (100)	0 (0)		
Did not specify	21 (11)	0 (0)	21 (13)		
Receives formal supervision				15.26	<0.001
Yes	68 (19)	17 (43)	51 (16)		
No	281 (80)	23 (57)	258 (83)		
Missing data	4 (1)	0 (0)	4 (1)		
No. leaders facilitating the group One	145 (41)	17 (43)	128 (42)	0.01	0.910
More than one	203 (58)	23 (57)	180 (57)		
Missing data	5 (1)	0 (0)	5 (1)		
Facilitating a group for a specific cancer type or stage of MS					
Yes	160 (45)	18 (45)	142 (45)		
No	190 (54)	22 (55)	168 (54)		
Missing data	3 (1)	0 (0)	3 (1)	0.01	0.923
Frequency of group meetings				4.14	0.042
More than one meeting a month	72 (21)	13 (33)	59 (19)		
One meeting a month or less	273 (77)	26 (65)	247 (79)		
Missing data	8 (2)	1 (2)	7 (2)		

The practical, personal and professional challenges endorsed by leaders were rank-ordered. The most commonly identified practical challenges associated with support group leadership included: being contacted outside of the group meeting (trained n = 16, 44%, untrained n = 129, 52%) a lack of leadership or counselling training (trained n = 10, 26%, untrained n = 138, 47%), and difficulty recruiting new members (trained n = 12, 30%, untrained n = 109, 36%). The most commonly identified professional and personal challenges associated with support group leadership included: difficulty to manage dominating group members (trained n = 13, 33%, untrained n = 87, 29%), a lack of support from health professionals

(trained $n = 13$, 35%, untrained $n = 102$, 35%) and the group stagnating (trained $n = 8$, 21%, untrained $n = 110$, 37%).

Using the total number of challenges, a significant difference ($t = -2.254$, d.f. = 317, $P = 0.025$, 95% CI: -16.47, -1.12) was found between trained (M = 123.0, SD = 16.7) and untrained support group leaders (M = 131.8, SD = 22.9), with untrained leaders indicating a greater level of challenges in the facilitator role. Challenges more commonly reported by untrained leaders included feeling guilty if they were unable to assist members, and a greater need for leadership or counselling training [than trained leaders ($P < 0.05$)] (see Table 3). Trained leaders more commonly reported the challenges of experiencing hostility from group members and having members at different stages of disease, compared with untrained leaders ($P < 0.05$) (see Table 4).

Rewards of support group leadership

On average, support group leaders scored 30 (SD = 3.5), out of a possible score of 35, on the rewards subscale, indicating a high degree of reward in their facilitator role. The most commonly cited rewards associated with group facilitation related to feeling good about witnessing a group member's progression in coping with their illness ($n = 335$, 98%) and that simply leading the support group was a rewarding experience ($n = 326$, 95%). Other common rewards included enjoying the opportunity to have a positive impact on the lives of members ($n = 317$, 93%) and the opportunity to be part of members' illness journey ($n = 321$, 91%). Leaders overwhelmingly agreed that the rewards of support group leadership outweighed the challenges ($n = 315$, 92%). No significant differences were found between trained and untrained support group leaders on the total of the rewards scale or on any individual items.

Psychological wellbeing of support group leaders

Leaders reported experiencing low levels of burnout, across all three subscales assessing Emotional Exhaustion (M = 10.5, SD = 10.6), Depersonalization (M = 2.9, SD = 7.5) and Personal Accomplishment (M = 51.4, SD = 19.0) (see Table 5). Trained leaders (M = 14.1, SD = 9.3) scored significantly higher than untrained leaders (M = 10.0, SD = 10.7) on the emotional exhaustion subscale ($t = 2.260$,

Table 3. Most common challenges of Untrained Support Group Leaders

Rank	Challenge	Untrained (n = 313)			Trained (n = 40)			χ^2	P
		Valid, N	n	%	Valid, N	n	%		
1	Members often contact me outside of meeting times	249	129	52	36	16	44	0.682	0.409
2	I would benefit from leadership/counselling training	294	138	47	38	10	26	5.793	0.016[1]
3	I sometimes feel that the group stagnates and has nothing to offer	305	110	37	39	8	20	3.711	0.054
4	It is hard to recruit new members to the group	306	109	36	40	12	30	0.491	0.483
5	It is difficult to convince health professionals that my group is an important part of treatment	294	102	35	37	13	35	0.003	0.958
6	I find it difficult to handle members who are particularly domineering	303	87	29	40	13	33	0.245	0.620
7	I feel guilty if I can't help group members with their needs	303	85	28	39	5	13	4.134	0.042[1]
8	It is hard to find a co-facilitator	284	80	28	34	10	29	0.023	0.879
9	Find it hard to encourage members to share responsibility for group organization	301	81	27	34	7	21	0.630	0.427
10	Find it hard to involve members in helping with administrative and practical jobs	289	77	27	31	7	23	0.239	0.625

[1]Significant at the $\alpha = 0.05$ level.

Table 4 Most common challenges of Trained Support Group Leaders

Rank	Challenge	% Trained			% Untrained			χ^2	*P*
		Valid, *N*	*n*	%	Valid, *N*	*n*	%		
1	Members often contact me outside of meeting times	36	16	44	249	129	52	0.682	0.409
2	I have experienced some hostility from group members	39	14	36	298	44	15	10.809	0.001[1]
3	It is difficult to convince health professionals that my group is an important part of treatment	37	13	35	294	102	35	0.003	0.958
4	I find it difficult to handle members who are particularly domineering	40	13	33	303	87	29	0.245	0.620
5	It is hard to recruit new members to the group	40	12	30	306	109	36	0.491	0.483
6	It is hard to find a co-facilitator	34	10	29	284	80	28	0.023	0.879
7	Having group members at different disease stages is difficult	38	10	26	298	40	14	4.423	0.035[1]
8	I would benefit from leadership/counselling training	38	10	26	294	138	47	5.793	0.016[1]
9	I need some kind of support to help me cope with the emotional issues associated with leading my group	38	9	24	294	67	23	0.015	0.902
10	I find it hard to involve members in helping with administrative and practical jobs in my group	31	7	23	289	77	27	0.239	0.625

[1]Significant at the $\alpha = 0.05$ level.

Table 5 Burnout

	Degree of burnout					
	Low		Moderate		High	
	Trained *n* (%)	Untrained *n* (%)	Trained (%)	Untrained *n* (%)	Trained *n* (%)	Untrained *n* (%)
Emotional exhaustion	25 (72)	176 (78)	6 (17)	29 (13)	4 (11)	21 (9)
Depersonalization	31 (86)	208 (90)	3 (8)	6 (2)	2 (6)	18 (8)
Personal accomplishment	30 (91)	167 (78)	0 (0)	18 (8)	3 (9)	30 (14)

d.f. = 315, *P* = 0.025, 95% CI: 0.53, 7.70), although this was still within the low range for burnout. Trained leaders also scored significantly higher (M = 59.0, SD = 17.3) than untrained leaders (M = 50.5, SD = 19.1) on the personal accomplishment subscale (*t* = 2.422, d.f. = 299, *P* = 0.016, 95% CI: 1.52, 14.73), indicating a greater level of personal accomplishment experienced by trained leaders.

On average, the depression, anxiety and stress levels of leaders fell within the normal range; depression (M = 3.0, SD = 4.8), anxiety (M = 2.1, SD = 3.4) and stress (M = 5.8, SD = 6.2). Compared with trained leaders (M = 1.5, SD = 3.1), untrained leaders (M = 3.2, SD = 5.0) reported a higher level of depression (*t* = −2.097, d.f. = 333, *P* = 0.037; 95% CI: −3.27, −0.10) (see Table 6).

Unmet support and training needs of support group leaders

The most commonly endorsed unmet support and training needs, identified by both trained and untrained leaders, related to receiving feedback from group members (trained *n* = 36, 90%; untrained *n* = 277, 93%), gaining access to a website with ideas and resources for leaders (trained *n* = 34, 85%; untrained *n* = 247, 83%), and a digital versatile disc (DVD) and manual with practical exercises for leaders (trained *n* = 32, 80%; untrained *n* = 297, 81%). Compared with untrained leaders (M = 3.6, SD = 1.0), trained leaders (M = 4.1, SD = 0.86) reported a higher level of need for supervision with a trained professional (95% CI: 0.11, 0.71) (see Table 7).

Table 6 Levels of depression, anxiety and stress

	Normal		Mild		Moderate		Severe	
	Trained n (%)	Untrained n (%)	Trained n (%)	Untrained n (%)	Trained n (%)	Untrained n (%)	Trained n (%)	Untrained n (%)
Depression	35 (95)	216 (90)	2 (5)	14 (6)	0 (0)	5 (2)	0 (0)	4 (2)
Anxiety	34 (92)	223 (93)	2 (5)	7 (3)	1 (3)	4 (2)	0 (0)	4 (2)
Stress	36 (97)	216 (90)	0 (0)	12 (5)	1 (3)	8 (3)	0 (0)	3 (2)

Table 7 Unmet needs of support group leaders

Support group leaders would benefit from	Trained (n = 40)		Untrained (n = 313)						
	Valid, n	% yes	Valid, n	% yes	t	d.f.	P	Mean diff.	95% CI of difference
Feedback from group members	40	90	297	93	−0.279	335	0.780	−0.028	−0.23, 0.17
The development of a website of relevant articles, resources and ideas	40	85	298	83	1.638	336	0.102	0.220	−0.04, 0.48
Watching a constructed video of a support group meeting and discussing critical points and potential interventions	39	82	290	67	1.929	55.9	0.059	0.234	−0.01, 0.48
The development of an interactive manual, which would include a DVD with practical exercises	40	80	297	81	0.265	335	0.791	0.037	−0.24, 0.32
Individual supervision with a trained health professional	40	80	286	60	2.720	55.9	0.009[1]	0.406	0.11, 0.71
The establishment of a support∕debriefing group which would meet on a regular basis face-to-face or by teleconference	39	64	289	57	1.256	326	0.210	0.196	−.11, 0.50
The opportunity for organised 'guest leaders' where group leaders would observe and exchange ideas	39	51	285	58	−1.015	322	0.311	−0.167	−0.49, 0.16
Confidential feedback on your own audio-taped group sessions from a central team	40	30	286	30	0.443	324	0.658	0.074	−0.26, 0.41

[1]Significant at the $\alpha = 0.05$ level.

Discussion

Challenges and rewards of support group leadership

The current exploratory study aimed to comprehensively document the experience of chronic-illness support group leaders in Australia. With an adequate response rate from a nationally recruited leader population, the results of the study can be regarded as largely representative of the Australian adult chronic-illness support group leader population.

The results suggest that the majority of leaders did not experience many challenges in their facilitator role. However, individual item analysis of the challenges subscale suggests that a large number of leaders are contacted

by members outside of group hours, and find member recruitment and establishing group credibility amongst health professionals difficult. The issues of recruitment and group credibility are intrinsically linked, with only one-third of leaders identifying medical staff as a means by which members hear about the support group. This is not an unusual finding with research into physician attitudes towards self-help groups concluding that although physicians generally view support groups positively, a concern regarding misinformation is a common barrier to support group referral.[27,28]

The management of difficult support group scenarios, such as dominating or shy members, added to the task of many leaders. A lack of group facilitation skills of some leaders, either perceived or actual, may have contributed to this finding. Indeed, trained leaders reported a lower level of challenges compared with untrained leaders, indicating that increased skill level may enhance the support group leadership experience. Certainly, this study demonstrates that there is a high demand for training amongst leaders, regardless of group facilitation skill.

Unexpectedly, significantly more trained leaders reported experiencing hostility from group members than untrained leaders. It is possible that members feel they can express hostility to a professional (often employed to facilitate the group) but not to a volunteer who runs the group in his/her free time and has a personal history of disease. Alternatively, patients may perceive professional leaders as part of the medical establishment and therefore accountable for unpleasant experiences, or it may be that professional leaders are more willing to disclose that they have experienced hostility. Further research is required to explicate this finding.

Of note is the one-third of leaders who reported difficulty finding a co-facilitator to assist them in their facilitation role. As almost half (42%) of the sample identified as sole-facilitators, this would suggest that many of these leaders had a preference for co-facilitation. Whilst there are both advantages and disadvantages to group co-facilitation, for leaders

who are inexperienced and/or lacking facilitation skills, co-facilitation can reduce leader anxiety and provide an excellent opportunity for feedback.[13] It is unfortunate that some leaders are not afforded this opportunity, especially considering the low number of leaders reporting access to professional supervision (20%).

Surprisingly, trained leaders reported a stronger need for supervision, despite the fact that they were already receiving significantly more supervision than untrained leaders. The lack of supervision of untrained leaders is concerning and may partly explain the higher level of challenge reported by this group. It is possible that leaders with basic or no training may perceive supervision as punitive or may not appreciate its value, as has been demonstrated in a study by Payne (2001).[29] In that study, supervision was provided for hospice-based volunteers but was not utilized, with volunteers reporting feelings of ambivalence, resentment and even hostility towards supervision. The authors conclude that the volunteers may not have understood or appreciated the importance of supervision. Educating leaders on the purpose and benefits of supervision may alleviate leaders' misconceptions or concerns, and should be included as part of any interventions to assist group leaders. Alternatively, and especially when working with volunteer leaders, 'user-friendly' terms for supervision such as 'support' could be introduced, as has been carried out in the UK, to facilitate its acceptance.[30]

This study provides evidence of differences between leaders trained and untrained in group facilitation, particularly in the structure and frequency of the support groups conducted. Trained leaders were more likely to be running more groups, more frequently, yet reported a lower number of challenges. Trained leaders also reported more years of experience as a facilitator, which may have ameliorated the burden of the increased workload reported by this group. Perhaps the expectations of trained leaders of themselves and of the group are different to that of untrained leaders, as many of the latter are volunteers with no group facilitation training. It is possible that untrained leaders follow an

educational-support model of support group (guest speaker, followed by informal peer support), which, theoretically, should be less demanding than the psychotherapeutic-support model (professionally facilitated education, training or therapy) because of the reduced need for group facilitation skills. Supporting this is the lower frequency of meetings facilitated by untrained leaders, predominately held on a monthly basis, and the smaller number of group members attending groups facilitated by trained leaders. Overall, the finding that untrained leaders reported more challenges, even though the groups they conduct may be less demanding, is concerning and the provision of adequate support and training for this subgroup of leaders is warranted.

In line with the existing literature,[20] leaders overwhelmingly endorsed the proposed rewards of support group leadership. As many leaders had a personal history of cancer or MS (59%), it is possible that leadership provided them with a way of giving this experience meaning. Research in this area has found that emotional expression and positive social experiences in discussing the cancer journey is associated with enhanced post-traumatic growth.[31] Indeed, almost 89% of leaders agreed they had grown personally as a result of leading their support group. Helper-therapy theory[32] may further explain the high degree of rewards experienced by leaders, as group leadership provides a direct means for the leader to carry out the helper role, and as such gain personally from their leadership role.

Psychological wellbeing

Previous studies have indicated that challenges associated with leading cancer support groups can adversely affect leaders' psychological well-being.[9,20] However, compared with normative data from a non-clinical population, the amount of psychological distress experienced in the current sample was in the lower range,[24,33] which is consistent with both previous studies[34,35] and the low degree of challenges reported by leaders. Results from the burnout scale (MBI-HSS) indicated that trained leaders experienced a

higher level of emotional exhaustion, and simultaneously, a higher level of personal accomplishment, compared with untrained leaders. As many of the trained leaders were facilitating more groups, more often, as part of their full-time employment, it is not surprising they experienced a higher level of emotional exhaustion (albeit, within a low level of burnout). It is also possible that work-related stressors external to support group facilitation may have contributed to this finding. Conversely, this subgroup also reported a higher level of personal accomplishment. This finding warrants further investigation, particularly if the higher level of personal accomplishment reported by trained leaders is ameliorating the effect of the emotional exhaustion, thus avoiding burnout.

Overall, leaders reported low levels of depression, anxiety and stress. Of note, untrained leaders reported a higher level of depression than trained leaders, although this was still within the normal range for psychological wellbeing. It is possible that leaders of chronic illness groups have good psychological health. Many leaders had a personal history of cancer or MS, which may have encouraged a more optimistic outlook, and a re-examination of what constitutes a challenge or barrier. Further to this, leaders in this study reported a high level reward associated with conducting a support group. The reported feeling of satisfaction, opportunity to be part of a member's illness journey, and seeing members' progress in coping with the illness, may have a protective effect against psychological morbidity. It is also possible that even though the survey was anonymous, leaders may have been influenced by social desirability bias. Certainly, amongst support group members, there is evidence to suggest that quantitative ratings tend to be more positive than qualitative reports.[36]

Needs of support group leaders

Regardless of the level of training or number of reported challenges, leaders agreed strongly with a number of unmet training and support needs. It is somewhat counter-intuitive that, overall,

leaders reported a low level of challenge in their facilitator role, yet strongly endorsed the need for further support and training. Similar findings have been reported by Wiggins and Carroll (1993).[37] This apparent paradoxical finding requires further investigation.

Obtaining feedback from group members was the most common unmet support and training need. Feedback helps leaders adjust to their role, reflect on their leadership performance, plan effectively and organize meetings to meet members' expectations, and as such it is not surprising that both trained and untrained leaders identified most with this unmet need. Access to a website with relevant articles, resources and ideas on group leadership, and a DVD with practical exercises were also highly desired. Ideally, these interventions should be developed and their efficacy evaluated by randomized controlled trial.

Limitations and strengths of the study

There are several limitations to the current study. The considerable diversity within the sample meant that it was impossible to have homogenous comparison groups. This may limit the conclusions drawn from this study. As this issue has not been investigated in the MS group leader population, the purpose-designed questionnaire was developed on the basis of studies investigating cancer support group leadership only.[9,20] However, the final questionnaire was piloted with both cancer and MS support group leaders and endorsed after minor revisions (using the word 'facilitator' rather than 'leader'). Nevertheless, it is possible that certain elements of group leadership specific to the leaders of MS support groups were omitted from the questionnaire. While beyond the scope of the current study, it would be beneficial to validate the purpose-designed questionnaire with leaders of other chronic illness support groups.

Future research

This study highlighted the diversity amongst support group leaders. This diversity, coupled with considerable variation regarding the defi-

nition of a support group leader[4–6], provides specific conceptual and methodological challenges when conducting support group research. In this study, data analysis was conducted based on the self-reported level of group facilitation training of the participant. It is possible that alternate categorization methods could have been used, for example, leaders' level of psychological training or of personal cancer experience. This would have led to four or five categories of leader type which may have better addressed the diversity amongst the group leader population. It is anticipated that more than one factor or a combination of factors may impact on the experience of support group leaders and this requires further investigation. Future research could determine what factors (apart from group facilitation training) impact upon the experience of support group leaders. For example, does being diagnosed with a chronic illness enhance or hinder an individual's ability to facilitate a support group? The assumption is that having a personal diagnosis assists with facilitation but this is yet to be definitively answered.

To date, the effect of leader behaviour on group member outcomes has been addressed in only one study which was limited to professionally trained leaders.[8] In light of the increased diversity amongst the support group leader population through a growing number of untrained volunteer peer-leaders, future research needs to assess if this diversity is translated into different experiences and outcomes for group members. Dependent on the outcome of such research, it may be appropriate to develop a set of minimum standards or process of accreditation for support group leaders to ensure that leaders are appropriately equipped to facilitate support groups.

Considering the large variation amongst groups and group leaders, it would be helpful to have a clearer understanding of the content of support group meetings, how they differ and what this difference is dependent upon. While reports from leaders about the type and function of their support group provide some idea of the groups' aims and structure, they do not provide

data on the actual exchanges between members and leaders. Ideally, a cross-section of support groups should be audio-visually recorded and audited to provide insight into the realities of a support group meeting.

Considering the multicultural composition of Australia, it is important that future investigations are not limited to support group leaders who are proficient in English. In addition, support group members no longer have to meet face-to-face in order to benefit from support group attendance, with studies documenting the effectiveness of online support groups.[38,39] Future research investigating the experience of leaders of internet and telephone support groups may identify additional barriers to group leadership not assessed in the current study, including moderating on-line group discussions, and ethical issues associated with a virtual world.

In this study, there was inconsistency between quantitative and qualitative findings reported by support group leaders. Further examination to fully understand this discrepancy is needed. This finding suggests a mix-method approach should be employed when conducting research with support group leaders.

This was the first study to systematically compare and contrast the challenges, rewards, unmet support and training needs, and the psychological wellbeing of support group leaders of chronic illness support groups with respect to level of group facilitation training. Findings point to the benefit of training and support interventions to assist group leaders, particularly leaders who are untrained volunteers. A substantial number of leaders in this study came to the role of leader with minimal or no training, and as such may not have been prepared for the demands on their time, energy and resources required by this role. There is evidence to suggest that group facilitation training enhances the leadership experience, and in turn, that of support group members. However, it is important to acknowledge that group facilitation training may not always be available or possible for leaders. In the absence of training, a possible solution may be for volunteers to involve a professional leader in the group, either through supervision or co-facilitation. Hence, addressing leaders' needs through the provision of interventions and/or by maximizing access and utilization of supervision will ensure that leaders' contribution to the group is positive, and the provision of high quality services to those with chronic illness is sustained.

Acknowledgements

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