

Title: Participants' experiences of and perceived value regarding different support types for long-term condition self-management programmes

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Abstract

Objectives: Health professional led group programmes are a common form of chronic condition self-management support. Much research has focused on clinical outcomes of group participation, yet there is limited research on how group participants perceive and experience the support they receive. We aim to identify the different types of support that participants receive from both facilitators and other participants, and how they value this support.

Methods: Semi-structured interviews were conducted with 20 participants taking part in a self-management group programme for a long-term condition (obesity, type 2 diabetes or chronic obstructive pulmonary disease). Data were analysed thematically, guided by Cohen's (2004) and Thoits' (2011) social support frameworks.

Results: Participants identified information and emotional support from both facilitators and other participants as complementary yet distinct. Facilitators' support came from professional training and other participants' support reflected the contextual, lived experience. Professional interactions were prioritised, constraining opportunities for participant-participant support to be received and exchanged.

Discussion: We identified a key gap in how self-management support is enacted in groups.

Engaging participants to share experiential knowledge will make group support more relevant and mutually beneficial to participants living with a long term condition.

Key words: self-management, group programme, long-term condition, qualitative

Introduction

The increasing prevalence of long-term conditions (LTCs) has created new challenges for health systems and health professionals in how to provide self-management support for people living with these ongoing and mostly progressive conditions. An often-cited aim is for health professionals to provide support that is person-centred and works in partnership with their patients with LTCs, by harnessing and enhancing patients' own capabilities to self-manage (1-4). Group programmes are a common format for the provision of self-management support in many countries including Australia. There is evidence that self-management support group programmes can improve clinical outcomes and have a positive effect on the activities of daily living (5, 6). However, there is also evidence showing that these programs have limited impact for more marginalised groups in the population (e.g. ethnically diverse and socially and economically disadvantaged people), who should benefit the most. This is because they tend to ignore the impact and relevance of people's social context and priorities (7, 8). For example, an individual living with a LTC may prioritise maintaining valued social relationships, roles and identities, whereas symptom management and clinical outcomes may be less personally relevant to them (9, 10).

Self-management support is articulated in national and international health policy as a way to extend the scope of LTC healthcare delivery, giving prominence to the needs of people with LTCs and enabling the inclusion of social and emotional dimensions of living with LTCs alongside medical and clinical aspects of these conditions (1, 11). It has been delivered using approaches based on different models (5, 12-17). The provision of self-management support through group programmes (either generic or condition specific) is typically facilitated by health professionals such as nurses, dietitians and physiotherapists. Evidence shows improved health outcomes for condition markers such as blood sugar levels in diabetes, health behaviour changes and utilisation of healthcare, although these are usually small and not sustained long-term (5, 7, 18-21). Research also shows the potential of group programmes for providing an environment of peer support, where participants can share experiences and gain condition-specific knowledge and strategies for self-management

(22). A recent systematic review (23) of the experiences of participants in self-management group programmes revealed the importance of social support, belonging, connectedness and shared learning with other group participants. However, research on the experiences of group facilitators of self-management support shows that their focus remains predominantly on providing evidence-based education and instruction for health behaviour change to participants, rather than on group member interactions and peer support (5, 24, 25).

There is no universally recognised definition of self-management support and the notion of what constitutes support is still under-developed. In particular there has been very limited research on how group participants perceive and experience support in group programs, how they describe and value the different kinds of support provided by facilitators and other group participants, and how they mobilise this support to help live with and manage their condition.

In this paper, we draw on Cohen's (2004) framework of support which suggests that support encompasses three main types – informational, instrumental and emotional. Informational support refers to information, advice or guidance; instrumental support refers to tangible assistance; and emotional support to 'expressions of empathy, caring, reassurance, and trust' and 'venting' (26). We also draw on the theoretical work of Thoits (2011) who proposes that the support provided by individuals with similar experiences is valued for their experiential knowledge and understanding of the 'many dimensions and nuances' of an individual's lived experience and situation (27). Similar others provide information and advice that is relevant, and empathy is expressed because it is drawn from personal experience (27-29). They can also act as role models for comparison, shaping coping responses and providing hope that proposed courses of action will be beneficial (27, 30).

In the context of health professional-led self-management programmes, where there is potential for support from both group facilitators and from group participants sharing similar experiences, there is still little known about what type of support participants receive from facilitators and participants, and what support they value. In this paper our aim is to identify the different types of support that

group participants in self-management support group programmes receive and exchange between both facilitators and peers, and how they value this support.

Methods

Approach

This paper draws on semi-structured interview data from individuals participating in self-management group programmes in New South Wales, Australia. Interviews explored participants' experiences and views of self-management support while participating in the programmes. Ethics approval was obtained from area health district and university ethics committees.

Sample

Participants (n=20) were attending a group programme (n=6) for one of three LTCs: chronic obstructive pulmonary disease, diabetes or obesity. Table 1 provides an overview of participant characteristics. Group programmes were purposively selected from a range of metropolitan and regional locations and hospital and community-based settings. All programmes were led by a health professional (see Table 2 for programme characteristics).

Table 1. Participant characteristics

Characteristic	Number
Gender	
Female	10
Male	10
Age	
Average	59
Range	27-80
Median	66
Condition	
Diabetes	6
Obesity	8
COPD	6
Education level	
School year 10 or below	2
School year 12 or equivalent	7
Trade certificate	5

University degree	5
Not disclosed	1
Employment status	
Employed full-time	2
Casual employment	2
Not currently working	16

Table 2. Programme characteristics

Site	Location	Condition	Facilitator types
1	Large metropolitan hospital outpatient gym	COPD	Physiotherapist
2	Small metropolitan hospital outpatient gym	COPD	Physiotherapist
3	Large metropolitan hospital outpatient room	Diabetes type 2	Dietitian
4	Suburban general practice	Diabetes type 2	Dietitian and exercise physiologist
5	Large metropolitan hospital outpatient room	Obesity	Physiotherapist, nurse, psychologist, dietitian
6	Rural, community hall / hospital meeting room	Obesity/ healthy lifestyle	Dietitian and exercise physiologist

Recruitment

A researcher introduced the study to participants during the course of the programme, describing the purpose and what participation would involve. Those who expressed interest were given an information sheet and invited to participate in an interview. All participants provided written consent prior to being interviewed.

Data collection

In-depth, semi-structured interviews were conducted face-to-face (in a mutually agreed location) or by telephone between December 2015 and April 2017. An interview guide was developed to explore experiences of participation in group programmes, and informed by LTC support literature and a

systematic review of the qualitative group self-management programme literature (23). Interviews explored experiences of living with and managing LTCs, experiences of participating in the group programme and interactions with group facilitators and other participants. Interviews lasted between 60-90 mins, and were audio recorded, then transcribed verbatim by a professional transcription company. All data were de-identified and participants were allocated pseudonyms.

Data analysis

Qualitative data software (nVivo 11) was used to manage and organise the data. The data were thematically analysed using a combination of deductive and inductive analysis. Interview transcripts were read repeatedly and categorised using the three theoretical component types of support provision – instrumental, informational and emotional – as a framework to consider the support described by group participants (26, 27). We were sensitive to descriptions of perceived versus received support; the source of support and; how participants talk about the value and meaning associated with support that they experienced during the programme; these formed the basis for our thematic analysis. In addition, emerging from the data were participants' views on different sources and types of support and how they were accessed in the groups. During this process we confirmed our interpretations were supported by returning to the original data, and met regularly as a team to discuss any areas of divergence.

Results

Participants discussed informational and emotional but not instrumental support from the group programme. They saw group facilitators and other participants as contributing different yet complementary forms of informational and emotional support for living with a LTC. Participants described filtering information from both other participants and facilitators, choosing what was valid and useful to them. They also highlighted that although they valued time in the sessions for interaction with other participants, these interactions were often shut down or not encouraged by facilitators. We cover each of these main themes in turn.

Complementary forms of informational support

Facilitators' professional training and the medical settings in which they worked enabled the provision of specific medically oriented informational support. In contrast, the informational support received from other participants drew on their accumulated experiences from daily living with their condition (i.e., their 'lay knowledge').

Participants described health professional facilitators as focused on 'factual' information and advice. They positioned the facilitators as having expert knowledge in the self-management of LTCs regarding medical aspects such as condition physiology, test results, medications and recommended foods and exercises. They appreciated the facilitators' interest in the field of chronic condition care, and their time learning and studying. Information and advice provided by facilitators was respected and endorsed by participants (e.g. 'she has legitimate answers to legitimate questions' (Rose, 69 years, COPD)) and thus participants placed a high level of trust in facilitators to provide accurate information and advice that would be in their best interests. Participants also privileged facilitators' knowledge by stating that they had 'the right' information and would advise the 'correct' course of action. This can be seen in the following excerpt from Gary where the biomedical or professional knowledge of the facilitator is legitimised, in part because of its exclusivity (i.e., controlled by health professionals). Gary mobilises the information that he understands, describing this as a strong motivating factor in doing strenuous exercise.

[The facilitator might say] "I want you to do this." And I'll do it because I respect his knowledge. He knows what he's talking about. And I know I've got to push myself. ... that's my motivator, I want to see my heart rate improve, because that's going to help the arteries, it's going to do a lot of good. (Gary, 73 years, COPD)

At times, however, participants perceived that the information provided by facilitators was too 'rigid', sometimes overwhelming ('too much' information), irrelevant and lacking insight into their personal circumstances. The following quotes illustrate how this one-way delivery of information led Dan to disengage:

This is a very formal, a more rigid educational [programme]...They're not finger wagers, but it's a, professorial at the lectern, rather telling us what we need to know rather than letting us discover what we need to know. (Dan, 52 years, obesity)

When group facilitators position themselves as high status or authoritative this can impede participants from developing knowledge about their condition and discovering ways to self-manage. Participants' accounts suggested that they felt like passive recipients of information, 'we just sit and listen to what he says' (Ken, 79 years, diabetes), when they wanted their own expertise and capabilities for independent learning to be recognised by facilitators and integrated. Fred, for example exclaimed 'we're not kids' and suggested many aspects of the information provided by facilitators were common knowledge. As also illustrated by Fred, facilitators may incorrectly assume (and inadvertently underestimate) the level of information participants in programmes have, and this can limit opportunities for informational support:

They say, 'oh yeah that fats no good for me or that much sugar is no good for me'. There's no need to go to the program to know that, because you can read it yourself. (Fred, 72 years, diabetes)

In contrast, participants described the informational support gained from other participants as different from that of facilitators and therefore complementary – it filled gaps in the informational support provided by facilitators. Other participants provided informational support gained from their experience of living with and managing their LTC(s), i.e. experiential ('lay') knowledge, that was more personally relatable and relevant to participants' own circumstances, needs, experiences and challenges. Knowledge from other participants was predominantly about practical strategies and information, and personal accounts of what has worked or not, and less narrowly focused on recommended treatments. Other participants were much more likely to provide information about managing the wider social and emotional aspects of self-management such as uncertainty, negative emotions and feelings, interpersonal relationships and relationships with other health professionals.

Participants talked about the importance of learning from other participants about their strategies and approaches to self-management because they shared similar conditions and struggles.

Something else to think about, ponder over, sort of think well that's not for me or, yeah, I could do that, that's a great idea. ...I'll look into that or, start thinking of questions, and getting answers. (Rose, 69 years, COPD)

They identified this as a key 'gap' in the informational support that was provided by group facilitators, who provided more generic information, but had limited understanding about the intricacies and specificities of living with and self-managing LTCs. For example, Kevin talked about his belief that health professionals present them with 'no choice' but to follow a restrictive diabetic diet. Despite displaying empathy with patients, he believed that health professionals are not fully aware of how burdensome it is for people with diabetes to adopt and sustain such a diet. In contrast, Ken valued the shared 'understanding' of others living with diabetes, arguing that information rooted in lived experience is 'more believable'.

[Health professionals] can empathise all they want, but they don't know what it's like ... if it was someone suffering diabetes sitting there, then she is giving us information from her own experience. Being a diabetic, that would make a quantum leap because then they're more believable. ... there's a difference between a dietician managing their life and eating healthy and having a proper meal size, because they've done it because they want to. They haven't had to do it because they've got diabetes ... it is harder for someone to do because they have to. (Kevin, 62 years, diabetes)

Similarly, Bill contrasted the theoretical knowledge from facilitators and the 'practical' knowledge from participants, revealing how he listened to other participants' experiences and used this information alongside the responses of the facilitator to form his own understanding.

Actual people with the disease or whatever, it sort of resonated more with me...just finding out, hearing more, and learning about something from someone who's not read it in a book, who's actually living it... I'd like to hear the theory from [the facilitator], but the practical stuff from other people. (Bill, 31 years, diabetes)

Being encouraged and feeling safe: valuing emotional support from facilitators and peers

Participants described the group environment as 'welcoming', 'comfortable' 'safe', and 'reassuring'.

They felt emotionally supported by both group facilitators and other participants, yet they distinguished between the nature of such support. Emotional support from facilitators was typically more explicit – it was described as being encouraged, being listened to and being responsive to their concerns. In contrast, even though interactions between participants were limited, the emotional support gained from other participants was described as more inherent or 'felt' – as a feeling of belonging, reassurance, acceptance and safety of being among others with similar experiences,

The emotional support provided by facilitators was further described by participants as being 'personable', 'empathic' and 'positive'. Relationships with facilitators were described as trusting and non-threatening. Many emphasised that they were treated as a 'person' rather than a 'patient' (contrasting past experiences with other health professionals). For example, Monica said she could confide in her facilitator about anything because she would be listened to and supported rather than judged and blamed.

I confide in them that I can't stop eating, I cannot stop eating. So she gave me her email address, and I've emailed her what I eat for a whole week. And she's going to go over it and sit down and talk to me and explain. (Monica, 36 years, obesity)

Others similarly felt comfortable to expose vulnerabilities or fragilities, without fear of being shamed, embarrassed or criticised – something that they had experienced or feared in other spaces. They talked about the reassurance they gained from the knowledge that social and emotional impacts of living with LTCs are 'normal' experiences.

I can ask [the facilitator] stuff about this disease that my doctor doesn't fill... Like is it normal to feel depressed; is it normal to feel you know like isolated...she gives you answers, or she gives you skills to deal with stuff...She has great experience, and she's got empathy, she treats everybody as an individual, which is really, really nice. She remembers your name and she listens to you. She reassures you that you're not going crazy, and that it's normal to feel this way, people do feel this way, so you're not alone. (Rose, 69 years, COPD)

I find them [facilitators] wonderful,...I think what it does is it allows me to be frail, you know, it allows me to have my own frailties without feeling embarrassed by them. (Mark, 68 years, COPD)

In contrast, the emotional support exchanged between group participants was rarely as overt as that provided by facilitators. Apart from a couple of instances – encouragement during exercise activities, in most cases- participants described emotional support from other participants as *felt*, or in the words of Gary, ‘subliminal ...you're not conscious of supporting someone or being supported’. This was expressed as a feeling of being among peers who were similar to them because of their shared experience of living with LTCs. Knowing their peers faced similar challenges and ‘struggles’ was described as a ‘leveller’ and led to feelings of inclusivity. Perceiving no hierarchies, by contrast to health professionals (in a position of authority) contributed to a ‘non threatening’, open and inclusive space, and a feeling of ‘safety’. Even though this was not demonstrated explicitly, participants felt their peers were non-judgemental because of their shared experiences, illustrated by Ruby and Gary:

I know people are doing the same thing, and struggling the same as me, and want to lose the weight like me, and are doing the same exercises...I get more out of it. 'Cause I know that I've got the support...they're [other participants] not judging me on how I look, or how I'm doing things, they're there to help me, they're there to actually give me the support I needed. ... not just giving me support because they feel pity for me. (Ruby, 27 years, obesity)

We're all there for the same reasons. You might have a million dollars and the next person's got nothing but we're still in the same boat. ...And that's the leveller...we're all there because we have a problem. (Gary, 73 years, COPD)

This sense of belonging and acceptance, not always present in spaces outside of the group, allowed participants to compare their situation to others and feel less 'alone', feel 'hopeful' (seeing others doing well), and that their experiences of illness were 'normal' and shared.

Most things that [other participants] Ken and Michael said that they do, I'm about the same. ...Makes me feel that I'm normal...that I'm the same as other people... I like it. (Fred, 72, diabetes)

I think what I like about being in the group is that it allows me to be more accepting of myself and my own limitations because I can see the limitations of other people. So I can be here and I can see some people are stronger than me, some people are weaker than me, some people breathe better, some people breathe worse, it just allows me to be in sort of like a peer group with the chests. (Mark, 68 years, COPD)

Participants also described being able to express their feelings, emotions and frustrations to an understanding audience. They felt confident the response from other participants would be accepting. For example, Mark talked about being 'allowed' to express how he felt:

it's supportive talk in a sense that it might be just, "oh, God that's hard, I'm buggered" you know, that sort of level of conversation which is fine. ...it just allows you to say how you feel and you know that they understand completely. (Mark, 68 years, COPD)

Constraining opportunities for peer support through group interactions

Opportunities for peer support through participant interactions, though seen as important to participants, were perceived to be shut down or not encouraged by facilitators. Thus they were few and mostly 'ad hoc', often fitted in between content or activities directed closely by the facilitators. Most participants felt they would have gained from more opportunities to hear from, and talk with,

other participants. A few however, said they actively avoided interactions with others in the group because this might trigger negative emotions that they perceived were unhelpful for them.

The facilitators and programme structure seemed, from the perspective of participants, to prioritise facilitator-directed aspects of the programmes such as education, instruction and activities (individual exercises or workbooks). Support from other participants, spoken about at length as important, appeared to be bracketed off from, or invisible to facilitators, who were described as not giving opportunities or space for group interactions or at times were active in shutting down interactions. Anna perceived facilitators were discouraging of participant-participant interaction and she questioned their motives for configuring the room in rows, not facing each other. Deb questioned whether the programme could even be described as a group, stating she had little knowledge of the other participants.

the way the room is set up.just looking forward. So, there's not much interaction that way. ...I don't know why they do it that way...it's less intimidating for people?...it doesn't make for people interacting. (Anna, 52 years, obesity)

We say good morning to each other but I don't really know the people that were there. I don't know anything about them at all. (Deb, 69 years, COPD)

Participants felt restricted in their opportunities for discussions and wondered what might have been missed by not interacting more with others. Participants would also have liked to have heard more of others' feelings and their experiences of coping. They suggested through hearing about the struggles of others they could view their own in context and thus perceive themselves more favourably:

I feel a bit more...it's more normalised. ...The other people are struggling with their own issues, the real people. ...[However,] there's not a chance for interaction and question asking, and how someone else has overcome. ...you're able to pick up little gems from other people. But again,

here, I think this is more a...and it's not a finger wagging, but it's kind of, this is the knowledge you need to have. (Dan, 52 years, obesity)

A few participants also felt there was an absence of opportunities to directly express how they were feeling and coping to other participants, believing this would have a positive impact on their emotions. For example, Rose spoke about following her regimen solo but had regrets about the supportive benefits she felt she had missed out on. Warren, was willing to come early or stay back to be given this opportunity:

Well the only thing that I regret in here is that I come in and I just do my sheet myself, I do my exercises, like if I need help I can go to her [the facilitator] if there's a problem ...In a way I sometimes think when I've been really low, I think if I just had somebody to talk to about this feeling, I might feel better. But I don't, so then I talk to [facilitator]. ...and she said, "Yeah, this is when you need to go and see your GP." (Rose, 69 years, COPD)

I reckon even if they had ten minutes after. I know people got to go to pick their kids up but even if they come ten minutes earlier you know and somebody just sit down and just say how hard'd you think it was this week it'd be alright. Because a lot of them'll say well, it'd probably be hard for them this week. (Warren, 33 years, obesity)

A few participants spoke of their reluctance to share their experiences with their health condition, and yet still valued the 'little chats' they had with other participants about their daily activities and common interests. These participants avoided talking about their LTCs in part because they wished to avoid negative emotions that this could trigger. As such, incidental interactions served a different function in that they relaxed and helped participants to 'settle in and feel part of the group' and made it 'fun':

It relaxes you. I think it's important.... We're not talking about "oh how's your lungs", you know. ...No-one ever says, 'oh yeah I'm bringing up, you know this' and "coughing and spluttering over

my husband". It's never mentioned. ...we know why we're all there. We just chat about other things...about life. ...No you don't talk about your illness. (Gary, 73 years, COPD)

Discussion

This study explored the perspectives of people participating in a diverse range of health professional-led group programmes providing support for LTC self-management, about the nature and type of support they received. Applying a social support theoretical framework (26) to our in-depth exploration of the experience of group programme participation has given new explanations for how participants perceive and value 'support' in this format. Our findings show that participants gained informational and emotional support from both health professional facilitators and other participants. A key finding is that participants distinguished between the different types of knowledge and emotional support offered by facilitators and peers in the groups, as well as the different origins and justifications of the types. Further, these different types of support had different meanings and value to them and, together, they found the different types of support to be complementary. Participants felt that one source of support had limitations, and that a broader range of support had been gained in the groups than in other healthcare and social encounters. However, opportunities for supportive interactions between peers were few as participants perceived them to have been constrained by health professional facilitators who prioritised health professional support.

Informational support from facilitators was seen as factual, providing the right or legitimate answers to participants. Yet, when presented as rigid and authoritarian education, it disempowered participants and reduced their engagement with programmes, confirming previous findings about the low value of this type of education (5). In contrast, support received from other participants was grounded in lived experience and rich with opportunities for knowledge about possible strategies and real examples of successes and failures for self-management. People valuing and seeking experiential knowledge from similar others is not a novel finding and the self-help movements and online patient experience boom has been well documented (31-33). Indeed, governments and other

organisations have themselves become promoters as the evidence for benefits have increased (32). Our study suggests that in the context of formal self-management programmes led by health professionals, participants have the opportunity to evaluate both professional expertise and experiential knowledge to form a broader, more relevant understanding, of their own situation and knowledge needs (34). Further, the perceived limitations of both health professional facilitators and of other participants are reduced by the presence of the other. Participants, when speaking of this complementarity, appeared to be more engaged with the programmes and their self-management than when speaking of expert information only.

As with informational support, emotional support that enabled participants to feel safe and reassured also differed by source. Emotional support from facilitators was perceived as overt and attentive, participants valued the professional care, reassurance and encouragement, whereas from other participants it was inherent and described as 'felt' among peers with commonalities and shared understandings. Thoits and others have suggested that perceived emotional support, such as that spoken about by the group participants, is (paradoxically) stronger and more consistently beneficial to health than received (overt) emotional support (26). Our study participants' responses were about the value of having emotionally 'safe' opportunities to chat with and observe others, and there were a number who spoke about the emotionally supportive value of non-condition interactions. Perhaps health professional oversight of face-to-face contact in this format is a unique enabler for people prone to isolation, and where other emotional support formats such as professional, online, self-help or peer groups do not appeal (32, 33).

Studies of group self-management participants' experiences have previously reported that opportunities to interact with peers can be limited in group programmes (23). Our study found participants viewed being with peers as providing supportive processes that are distinct from those of health professionals. Thoits suggests support from similar others directly affects physical and mental health and indirectly buffers harmful physical and mental effects (27). However, research has shown health professional facilitators do not always prioritise this form of support and professional

authority, evidence-based education and narrow biomedical conceptualisations of self-management support prevail (24, 25, 35). Little group-specific training of health professional facilitators has been found in the literature (23).

The participants in our study, as in other studies (36), revealed they had compared themselves with others, which assisted with feelings of normality and perceived greater sense of hope. Uniquely in this study, participants reported that through these processes of perceived support from others they felt more motivated and engaged with their health. These outcomes should be of interest to researchers, practitioners and policy makers in the ongoing quest for patient engagement and activation with self-management (37, 38).

Strengths and limitations

A study strength was that we conducted purposive sampling in order to gain breadth and richness of experience across a range of conditions and programmes. Limitations in our study included that participants self-selected into the study. This may mean that other viewpoints were not captured in our data, such as from those who feel group self-management is unsuitable, who dropped out of the programme or were less engaged. A further limitation is that only one interview was conducted per participant. Future studies may wish to explore other group programme settings and use multiple time points before, during and after programmes.

Implications for clinical practice

Participants exposed some of the limitations of formal self-management support provided by health professionals in group programmes, as well as some opportunities. The group programmes in our study were perceived by participants as prioritising health professional and medical authority over exploration and nurturing of support for mutual benefit among the group participants. The 'invisibility' of the support that participants perceived and valued highly from peers may pose difficulties for health professional facilitators in the programme frameworks and medical contexts they operate within, which frequently use measurable biomedical outcomes to define success (5,

24). Practitioners facilitating group self-management support programmes should be aware of the limitations inherent in professional expertise revealed in this study to people seeking support with self-managing LTCs. Allowing space for making explicit the inherent support of peers and promoting experiential knowledge should make group self-management support more relevant to participants. This should be key to health systems and health professionals with aspirations to positively affect the lives of people with LTCs.

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Appendix 1. Interview guide questions

1. Living with a LTC

Tell me a bit about yourself

What kind of things do you do to manage your condition?

Has the way you manage your condition changed over time?

2. Group program discussion

How did you come to be in this group program?

Can you tell me a bit about your experiences of being in the group program?

What do/did you hope to get out of attending this course?

What do you think the group leader's role is?

How have you found the course material?

3. Plans for your health

What plans do you have for your future health?

After you finish the program, how do you think the way you manage your [] will change? Why?

How do you feel about the future when living with []?