


“An Expanded Window of Understanding a Changed Everyday Life”—Experiences From Patients With Long-Term Conditions After Attending Group Learning Sessions

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Abstract

Objective: Health education programs using group learning sessions for patients with long-term conditions have been tested, but not evaluated. In order to evaluate such sessions, the purpose was to explore experiences from patients with long-term conditions after participating in group learning sessions. **Methods:** A descriptive design based on qualitative content analysis was used. Interviews were conducted with 19 patients with different long-term conditions, and participants were asked about their experiences after taking part in the group learning sessions. **Results:** Sharing experiences with one another gave them opportunities for learning. Patients described a metaphorical “expanded window,” which opens in the group learning sessions; comparable to encounters during regular visits to health care providers. The nature of the learning environment that follows the educational model, together with describing lived experiences, allowed patients to share capability and resources, which was found to be foundational. **Conclusions:** The health education program as a format was important for shared learning. The facilitator can support the learning by structuring the format, but most essential was sharing experiences that facilitated each patient’s learning that can aid the support of individual self-management.

Keywords

long-term care, patient education, patient engagement, patient perspectives/narrative

Introduction

The ability to self-manage (note 1) is central when a patient is diagnosed with a long-term condition, because it can affect outcomes for both the patient and their relatives. The self-management process can improve the patient’s lifestyle, adherence, and empowerment (1). Although self-management is a personal task, patients may need support (2). Interventions that only focus on education will not affect self-management and behavioral change in people with long-term conditions. To be successful, interventions should appeal to a patient’s motivation and self-efficacy (3). Therefore, self-management interventions should be designed to support people with long-term conditions and how to deal with medication, symptom control, and emotional reactions of disease in daily life (1). Moreover, self-management programs that mainly focus on what providers decide is important, rather than what patients think is important, have not

been successful when it comes to supporting patients with strategies to improve their self-management (4). Also, it has been described that fellow patients can form mutual partnerships, and in contact with others, a sharing of experiences can provide emotional support. This perspective is missing when providers take the lead in self-management programs (5). Bringing a social environmental dimension to

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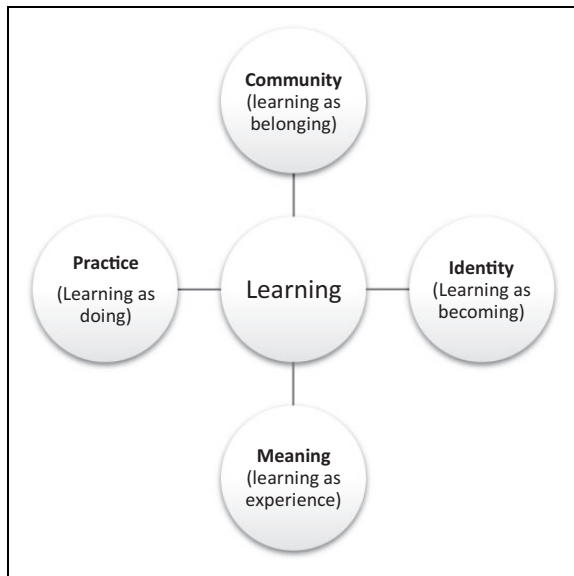


Figure 1. Components of a social theory of learning “communities of practice.” Adapted from Wenger 1998 (9).

self-management support by providing socially based options to improve health and well-being has shown to be successful (6,7). This social dimension is based on deepening relationships within personal communities of support—such as personal networks—that link both social activities and the management of health and well-being of the members of the community (7).

Being diagnosed with a long-term condition leads to many questions and traditionally, patients seek answers from their health care provider. Questions about adjustments, how to cope with changes and fears are issues that become central, and it may be difficult to receive answers to these questions from the provider (8); therefore, shared learning becomes a key aspect. Understanding how patients together may support each other in their self-management is an aspect that is not well investigated. By placing learning in the context of lived experiences and assuming that learning is a part of human nature, the process becomes a part of a social participation, which is central in the model communities of practice (CoP). Communities of practice is defined as groups of people who share something that they are knowledgeable about and interact regularly in order to learn how to do things better. This model is based on a social theory of learning where learning has 4 central parts; *learning* in practice (learning by doing), *community* (learning as belonging), *identity* (learning as becoming), and *meaning* (learning as experience). All 4 parts are seen as interconnected with each other (9) (Figure 1). Furthermore, this social theory of learning can be applicable in the program for health education, as described by Landtblom (10). This program points to a movement of attention from the provider’s perspective to the patient’s own understanding and ability to act. The central focus is on the patient’s subjective experiences and to increase their sense of control. It starts with a collection of

Table 1. Description of Participants and Number of Rounds of Group Learning Sessions.

Men		11 (58%)
Women		8 (42%)
Age groups		
18-34		1
55-74		13
75>		5
Diagnosis		Number of rounds ^a
Atrial fibrillation	11 (58%)	4
Chronic kidney disease (CKD IV)	2 (11%)	1
Depression	1 (5%)	1
Stroke	5 (26%)	2

^aRelates to number of occasions that the health education program was offered at each department.

facts from the group describing experiences, processing information together, and then analysing the causes. After shared conclusions, a plan for solutions and realistic plans for action is undertaken. A health education program is led by a moderator and often consists of regular physical meetings during a defined time; a start and an end (10). This form of health education program has been tested over several years in groups comprised of patients with long-term conditions, but how the learning process evolves has not yet been explored. Therefore, the aim was to explore experiences from patients with long-term conditions after participating in group learning sessions in order to understand more about the learning process.

Methods

Design

An explorative design with a qualitative approach was used in order to elucidate the experiences of attending group learning sessions during the health education program (11).

Health Education Program—Group Learning Sessions

The group learning sessions were inspired by the health education program developed by Landtblom (10). All participants taking part in the group learning sessions had experiences from similar diagnoses of long-term conditions, but the length of time following diagnosis differed (Table 1). The purpose of attending group learning sessions was to meet other people sharing the same diagnosis and to share common knowledge and learn together. A nurse at each department invited the participants and they met 5 times during a period of 6 months. The group constituted of 5 to 10 participants. Each session was led by a facilitator that was either a manager or a nurse. On the first occasion, participants in the group decided the content for the future sessions (the 4 upcoming sessions) by choosing, for example, if an expert should be invited. An expert could be a doctor, a dietician, or a librarian. Topics of interest were discussed and submitted to the experts in advance and participants

could ask questions during the session. The manager/nurse was responsible for taking notes and distributed the notes to all participants after each session (10). After the final session, participants were asked if they wanted to share their experiences to a researcher. If they agreed to participate, they gave their phone number or email address to the researcher who contacted each participant and planned for an interview (12).

Participants and Data Collection

A sample of convenience was used and to be eligible, participants should have attended at least 4 of 5 sessions (in order to answer the research question), and be able to speak and understand the Swedish language. Between 2015 and 2018, a total of 8 different rounds of the health education program were performed (Table 1). In total, 19 patients were interested in participating in the interview. Thirteen participants were interviewed in a separate room at the hospital and 6 participants were interviewed by telephone. In the interviews, 2 open-ended questions were used: describe what you think is happening in group learning sessions; and describe what and if group learning sessions have made any difference when it comes to managing your condition. Questions were pilot-tested in the first 2 interviews, only probing questions (why, explain more) were added and interviews were therefore added in the sample. The interviews varied in length from (approximately) 20 to 60 minutes and all interviews were recorded and transcribed verbatim by the first author. The interviews were performed 2 to 6 months after the participant had ended the program. All participants lived in their own homes.

Data Analysis

Data were analyzed according to inductive content analysis (13). In the preparation, all transcribed text was read through several times to gain an understanding of the content. Then, units for analysis were selected, which were sentences or several meanings that were associated with the aim of the study. During the organization phase, the focus was to become immersed in the data; the authors went back and forth between selected sentences and the original text. If several meanings were selected, a condensation was used to reduce the text (14). In the next step, the meanings and sentences were given a code, still close to the original text. During the open coding phase, codes were divided into categories and grouped under higher order headings. Similar categories were collapsed to reach higher order categories. In the analysis, 1 main category, 2 generic categories, and 5 subcategories emerged. To reach trustworthiness in the analytic procedure, 2 authors were responsible for the analysis (A.L. and C.P.) and after a preliminary analysis was performed, 2 other authors (B.H. and A.N.) were involved to discuss the preliminary results and then added their perspectives until all authors reached consensus about the results.

Ethical Considerations

The ethical principles for autonomy, beneficence, nonmaleficence, and justice were considered as stated in the Declaration of Helsinki (15). Verbal and written information about the study was given to each participant before they gave their informed consent to take part in the present study. The Research Ethics Committee at the Faculty of Health Science at Linköping University, Sweden, approved the study (D-nr: 2014/405-31).

Results

The patients' experiences of learning described after participation in group learning sessions were illustrated by "an expanded window of understanding a changed everyday life." Being part of group learning sessions was valuable to patients because of the opportunity to gain a better understanding about how to handle a changed everyday life, which is the main category (Table 2). The chance to meet other people who shared experiences that could be communicated to each other was highly appreciated by participants and was expressed as an "open window," which was more open in the group learning sessions, comparable to a regular encounter with a health care provider, described in the "nature of a learning environment." This presented possibilities to understand and process shared experiences and knowledge with fellow participants, which also affected how to live and handle everyday life, following the changes brought about by the medical diagnosis, described in the generic category "encouraging capability and resources." The 2 generic categories are described below in the text and with an overview illustrated in Table 2, which also contains citations from the participants.

Nature of a Learning Environment

This category illustrates the importance of a learning environment, which was expressed as a prerequisite for shared learning. For example, the facilitator that led the sessions interacted with each participant in the group and held everything together which promoted and moved the sessions forward. The facilitator held together, supported the selection of topics that the group wanted to know more about, and invited visiting experts such as physicians, dietitians, and physiotherapists.

The nature of a learning environment by following the structure of an educational model was expressed as supporting the participants' learning. It could sometimes be difficult to remember what was said after leaving the session, but receiving a written summary after the sessions helped them remember and process the content between both sessions and ending of the program. Participants were given an agenda such that they could prepare themselves prior to the next meeting. Because the facilitator wrote the summary, participants could concentrate on the discussions and later receive the written summary. Rules were created for the sessions including anonymizing any questions that the participants

Table 2. Overview of the Linkage Between Main Category, Generic Categories, and Subcategories that Emerged in the Analysis.

Main category	Generic category	Subcategory	Citations
An expanded window of understanding a changed everyday life	Nature of a learning environment	By following the structure of an educational model	"... what gave me the most was the experience of meeting others but there was too little time to talk about it..." (Patient with Stroke)
		By possessing professional competence	"We met a large spectrum of professionals in the group sessions... both physicians, psychotherapists, librarians... which was great... really good. There was many question marks that were corrected..." (Patient with Atrial Fibrillation)
		By creating content together	"We were the ones who influenced the content, I do not remember everything but... yes... but I think that either someone of us asked or said what professionals we might wanted to invite..." (Patient with Stroke)
	Encouraging capability and resources	By reassurance in sharing lived experiences	"I was one of those who had more experience... as I understand they [professionals] had put together a group because we were the one who got this... and we could support each other..." (Patient with Atrial Fibrillation)
		By sharing advice contributing to knowledge and skills	"One see that you are not alone there... the disease leave you with the feeling that you are alone in this... no one feels the way I feel... no one understands me but all of a sudden you have three four people who... really understand how it actually is... it's a fantastic source of self-esteem I believe... and you feel much better..." (Patient with Depression)

had, which was appreciated by participants since sensitive questions were not connected to them. Sometimes, not enough time was spent on questions, and this could be a limitation. Some expressed that being part of the group learning sessions did not affect them to a wider extent, but that it felt nice to be there.

The nature of a learning environment by possessing professional competence was also expressed by participants as important. Participants expressed the value of meeting different professionals, which gave them time to both ask questions, and time to receive thorough descriptions about the specific disease. Meeting the experts promoted understanding about the specific condition and gave participants new knowledge about how to individually deepen their own knowledge by offering advice and tips on literature to read and routines to test. Additionally, patients described the benefit of being able to give "experts" knowledge of their own lived experiences.

The nature of a learning environment by creating content together was also expressed: each participant's presence in the group was important and decisive. This was illustrated by the perception that sometimes too little time was spent on sharing their own experiences. Still, it was concluded that the format of participants deciding together which professionals to invite was important and valuable.

Encouraging Capability and Recourses

The second generic category illustrates the ability to share common experiences, something which was taken

advantage of during the shared learning. Encouraging capability and resources by reassurance in sharing lived experiences was described as the importance of contributing with own lived experiences and knowledge with each other. The participants described themselves as being in focus and that their presence was highly valuable which was considered as being a contrast to the traditional encounter with the physician or the nurse. Being there as a person with lived experience gave them the feeling of "being chosen" and that their experiences were taken seriously and added a feeling of encouragement and comfort.

The participants could also encourage capability and resources by sharing advice contributing to knowledge and skills, because they generously gave each other advice and shared how they had tested the advice they received from professionals, and what it had brought to their day-to-day lives. The sharing of experiences led to an increased understanding of their condition and how it could affect everyday life and ability to self-manage. This could potentially lead to the feeling of more power: a consideration expressed in their requirements when visiting their health care provider. Another impression was that the group learning sessions led to a feeling of being secure, which could lead to a changing attitude toward a more positive feeling of life again.

Discussion

It is the sharing of experiences with one another that gives opportunities for learning. The metaphorical "expanded

window” is described, which is more open in the group learning sessions, when compared with regular encounters with health care providers. The nature of a learning environment by following the educational model, and the sharing of experiences by encouraging each other’s capability and resources, is found to be central in supporting self-management. The results are discussed in the light of the components in the social theory of learning—CoP (Figure 1).

In a learning environment, the important role of the facilitator is to interact with members of the group and hold them together. The benefits of a program facilitator and how the facilitator behaves toward the participants, interacts and communicates the sharing of knowledge, has been found to be important elsewhere (16,17). To develop a learning environment, an increased understanding about how experiences can be shaped by the environment and by the attachment to a community is important (17). Meeting experts can promote understanding about a condition, leading to new knowledge about how each participant can deepen their own knowledge, and give something back to the experts. Being a part of a group can shift the relationship between patients and providers. An inherent power shift between patients and providers has been found (17), meaning that a group can foster an environment in which patients can feel that providers also can gain knowledge from patients. Furthermore, the interaction with group facilitators and other patients can facilitate participation and sense of hope (18). However, when the content is formed, it is important that it is related to the patients’ goals and not to the providers’ goals about what is essential in everyday life. The keys to patients learning must be identified and specified in the process when the content is created. There may be a difference between what the participants describe as learning goals and the learning that actually takes place during the sessions (19). In the social theory of learning, belonging to a *community* where participating is recognizable as competence, together with *practice*, where the learning happens in doing it together, participants can share frameworks and perspectives which can sustain the group’s mutual engagement (Figure 1), which was found in the present study. Consequently, the facilitator’s role to support activities that enables patients’ participation during the group learning sessions is central in promoting the shared knowledge translation between patients and experts.

Encouraging capability and resources is important, together with the contribution of shared lived experiences and knowledge. This has also been found in a study of survivors from lung cancer, describing their experiences as a journey. After the quest for survivorship, they had a need for learning about the disease and later on for advocacy and helping others (20). Also, sharing lived experiences has been described as more appreciated comparable to the educational part during an intervention for adults with heart failure (21). Basing interventions on sharing lived experiences of not being alone in the struggle may provide opportunities for

many patients to spontaneously describe and share their own stories and challenges. This, in turn, can build the sense of community for those participating in the group and support them in developing self-management tools (17,21). Also, being able to engage with each other can be helpful and facilitate motivation during the learning process. To recognize the ability to be supportive to one another and to better self-manage the long-term condition has been described (17), which supports the results reported in this article. The component “*identity*” (learning as becoming) is a way of talking about learning changes and the creation of personal histories in the context of the community (9), which links to these results (Figure 1). Sharing common experiences can serve as a source of identity construction in a group. It shifts the attention from the learning process to the relationships and exchanges that are going on between the members of the group. It has been found that CoP is a powerful mechanism for solving problems (22). Mobilizing the capability of a group working together can be a useful pathway to support changes because it highlights the process of engagement with the current concerns of individuals and the group members (7). These point to the results showing that sharing experiences can lead to patients gaining an increased understanding of their health condition and how it affects everyday life, leading to the feeling of empowerment. Being a part of a group sharing a common ground can improve the sense of social connection as it seems to eliminate the feeling of being isolated (23,24). The link between self-management and changes in social interactions highlights the importance of being part of a social community as well as the surrounding environment (21,23). The *meaning* as in learning as experience described in the social theory of learning is the way participants talk about the ability to change—both individually and collectively—if it is experienced as meaningful to be part of the group (9). Others have also described community as vital and include the value of sharing knowledge with others who understand the unique situation (20). In group learning sessions with people with eating disorders, participants describe that attending the group helped them to clarify personal values outside their condition and how to prioritize recovery and encourage one another toward behavioral change (25). Therefore, supporting each other from the basis of knowledge gained from lived experiences adds a perspective that a meeting with health care providers cannot present to that extent. The relational aspect of being a part of the group should not be underestimated, but individual differences are present.

Methodological Considerations

Due to the sample strategy, participants may be less willing to share negative experiences about the studied phenomenon, which may have affected the results. The time of collecting data was extended due to when the rounds occurred (about 1-2 each semester). This may have affected the results, since problems with recounting the memory of own

experiences may have been affected. Another limitation is that the total number of participants in each round was unknown to the research team, but according to the use of a qualitative design, this limitation has less influence on the study results. Thus, participants had attended different group learning sessions and had experiences from several long-term conditions which can strengthen the study results (25). Trustworthiness has been strengthened by describing the analytical procedure and involving several researchers who have experience in qualitative research. Transferability is assured by describing participants and the educational format, but given the study design, the results can only guide the future direction of planning and performing health education (12).

Conclusions and Clinical Implications

This study evaluates a health education program based on group learning sessions by describing patients' experiences and we conclude that the health education program as a format is important for shared learning to occur. The role of facilitator should not be underestimated because they can support the learning by structuring the format. Most important is the sharing of experiences in which the participants' capability and resources are central aspects in the learning process which can support the self-management process. For future directions, more research into effects related to health education should be explored and interventions where patients coproduce the content and lead sessions would be a way forward. We recommend using the power of fellow patients where they can share advice and support each other. We also recommend empowering patients to decide what the content of group learning sessions should focus on. These 2 recommendations can be powerful elements in the care of people with long-term conditions, which handle their self-management on a daily basis.

Declaration of Conflicting Interests

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Note

1. Self-management addresses the ability to manage symptoms, treatments, and lifestyle changes and physical, psychological, and cultural consequences of a health condition. Richard A. & Kimberly S. (2011). Delineation of self-care and associated concepts. *J Nurs Scholarship*, 43(3), 255-64. doi:10.1111/j.1547-5069.2011.01404.x

References

1. Hellqvist C, Dizdar N, Hagell P, Berterö C, Sund Levander MJ. Improving self-management for persons with Parkinson's disease through education focusing on management of daily life: patients' and relatives' experience of the Swedish National Parkinson school. *J Clin Nurs*. 2018;27:3719-28.
2. Kendall E, Ehrlich C, Sunderland N, Muenchberger H, Rush-ton CJCI. Self-managing versus self-management: reinvigorating the socio-political dimensions of self-management. *Chronic Illn*. 2011;7:87-98.
3. van Hooft SM, Been Dahmen JM, Ista E, van Staa A, Boeije HRJJ. A realist review: what do nurse-led self-management interventions achieve for outpatients with a chronic condition? *J Adv Nurs*. 2017;73:1255-71.
4. Warner G, Packer TL, Kervin E, Sibbald K, Audulv Å. A systematic review examining whether community-based self-management programs for older adults with chronic conditions actively engage participants and teach them patient-oriented self-management strategies. *Patient Educ Couns*. 2019;102:2162-82.
5. Dwarswaard J, Bakker EJ, van Staa A, Boeije HR. Self-management support from the perspective of patients with a chronic condition: a thematic synthesis of qualitative studies. *Health Expect*. 2016;19:194-208.
6. Bickerdike L, Booth A, Wilson PM, Farley K, Wright K. Social prescribing: less rhetoric and more reality. A systematic review of the evidence. *BMJ Open*. 2017;7:e013384.
7. Vassilev I, Rogers A, Kennedy A, Oatley C, James EJHE. Identifying the processes of change and engagement from using a social network intervention for people with long-term conditions: a qualitative study. *Health Expect*. 2019;22:173-82.
8. Kleiner-Fisman G, Gryfe P, Naglie GJP. A patient-based needs assessment for living well with Parkinson disease: implementation via nominal group technique. *Parkinsons Dis*. 2013;2013:974964.
9. Wenger E. *Communities of Practice: Learning, Meaning, and Identity*. Cambridge University Press; 1999.
10. Landtblom AM. Hälsoepagogik för vårdare och brukare i samarbete: en introduktion till bemästrande. In: Vifladd EH, Hopen L, eds. Stockholm: Bilda förlag; 2010.
11. Creswel JWJ., Lau NL. *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. Thousand Oaks, USA: Sage publication; 2009.
12. Polit DF, Beck CT. *Nursing Research: Generating and Assessing Evidence for Nursing Practice*. Lippincott Williams & Wilkins; 2008.
13. Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs*. 2008;62:107.
14. Graneheim UH, Lundman BJ. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*. 2004;24:105-12.
15. Organization WMA, Bot WH. World medical association declaration of Helsinki: ethical principles for medical research involving human subjects. *Bullet World Health Organ*. 2001;79:373.

16. Laursen DH, Frølich A, Christensen UJS. Patients' perception of disease and experience with type 2 diabetes patient education in Denmark. *Scand J Caring Sci.* 2017;31:1039-47.
17. Housden L, Browne AJ, Wong ST, Dawes MJHE. Attending to power differentials: how NP-led group medical visits can influence the management of chronic conditions. *Health Expect.* 2017;20:862-70.
18. Luhr K, Holmefur M, Theander K, Eldh ACJP, Counseling. Patient participation during and after a self-management programme in primary healthcare—the experience of patients with chronic obstructive pulmonary disease or chronic heart failure. *Patient Educ Couns.* 2018;101:1137-42.
19. Gunnarsson R, Runesson U, Håkansson P. Identifying What Is Critical for Learning 'Rate of Change': Experiences From a Learning Study in Sweden. *Theory and Practice of Lesson Study in Mathematics: Springer;* 2019:441-56pp.
20. Dy SM, Janssen EM, Ferris A, Bridges JF. Live, learn, pass it on: a patient advocacy engagement project on the lived experience of lung cancer survivors. *J Patient Exp.* 2017;4:162-8.
21. Sentell T, Kennedy F, Seto T, Vawer M, Chiriboga G, Valdez C, et al. Sharing the patient experience: a "talk story" intervention for heart failure management in native Hawaiians. *J Patient Exp.* 2019:2374373519846661.
22. Nicolini D, Scarbrough H, Gracheva JJTO. Communities of practice and situated learning in health care. In: Ewan F, Kathleen M, Anne Reff P, eds. *The Oxford Handbook of Health Care Management.* 2016:255-78.
23. Johnston S, Irving H, Mill K, Rowan MS, Liddy CJBFP. The patient's voice: an exploratory study of the impact of a group self-management support program. *BMC Fam Pract.* 2012;13:65.
24. Göransson C, Wengström Y, Ziegert K, Langius Eklöf A, Eriksson I, Kihlgren A, et al. Perspectives of health and self-care among older persons—to be implemented in an interactive information and communication technology—platform. *J Clin Nurs.* 2017;26:4745-55.
25. MacNeil BA, Hudson CCJ. Patient experience and satisfaction with acceptance and commitment therapy delivered in a complimentary open group format for adults with eating disorders. *J Patient Exp.* 2018;5:189-94.

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