

PROMOTING PATIENT AND CAREGIVER ENGAGEMENT IN SELF-MANAGEMENT OF CHRONIC ILLNESS

GUEST EDITORS: ANNETTE DEVITO DABBS, MI-KYUNG SONG, SABINA DE GEEST,
AND PATRICIA M. DAVIDSON





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Editorial

Promoting Patient and Caregiver Engagement in Self-Management of Chronic Illness

Annette DeVito Dabbs,¹ Mi-Kyung Song,² Sabina De Geest,³ and Patricia M. Davidson⁴

¹ *School of Nursing, University of Pittsburgh, Pittsburgh, PA, USA*

² *School of Nursing, UNC-Chapel Hill, Chapel Hill, NC, USA*

³ *Institute of Nursing Science of the Faculty of Medicine at the University of Basel, Switzerland*

⁴ *Faculty of Health, University of Technology, Sydney, Australia*

Correspondence should be addressed to Annette DeVito Dabbs; ajdst42@pitt.edu

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As a nursing professional you are no doubt aware of the growing prevalence of people with chronic conditions and the problems they face interacting and getting support from health care systems that are designed to deal with acute problems. Chronic diseases, such as heart disease, stroke, cancer, respiratory diseases and diabetes, are by far the leading cause of morbidity and mortality in the world [1]. Furthermore, more than half of individuals with one chronic condition have multiple chronic conditions, increasing the complexity and burden of managing their health.

Chronic conditions require a life-long care perspective. Support for patient's self-management is an essential component in the care of the chronically ill in order to guarantee favorable outcomes. Self-management has been defined as the individual's ability to manage symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition [2].

Patients and families are often on the front-line managing chronic illness between formal contacts with their healthcare providers. Effective self-management of chronic conditions requires patients and families to be engaged in their care in the face of dynamic changes in disease condition, complexity, symptoms, burdens, support and coping resources. Certain events and points of transition arise over the course of illness and make patients and families more vulnerable when their ability to perform self-management and maintain their quality of life is threatened. Due to the dynamic nature of chronic illness, patients' and families' needs for skills, information and support vary at different points in time, environments and

situations. Because of the dynamic realities of living with a chronic condition, they need a repertoire of self-management skills to deal with the unpredictable and sudden variations.

All of the papers in this special issue inform the science of self-management. Several authors employed integrated review and meta-analytic techniques, including Altman Klein and colleagues whose review identified the need for more responsive and dynamic education interventions for self-management of diabetes; G. S. Rasmussen and colleagues' integrative review of the problems and vulnerability associated with having psoriasis during adolescence; the study conducted by E. Kendall and colleagues points to the need for a more ecological model for the management of illness that actively engages consumers in social relationships and addresses the context within which their lives (and illnesses) are enacted; and the mapping of the literature regarding patient engagement conducted by S. Barelló and colleagues which revealed several emerging challenges to promoting patient engagement.

Other authors presented interventions to promote self-management in specific patient populations, including Hellström and colleagues for children with long-term illness to make a healthy transition as they enter school; J. Yang for Korean Patients with Chronic Hepatitis B; and B. L. Faett and colleagues for persons with chronic lower limb edema.

Perhaps not surprisingly because of the complexity of the topic, many of the original research reports that were selected for publication relied on qualitative inquiry, including phenomenography, grounded theory, qualitative description,

bibliometric and qualitative content analysis and interpretations of visual data of behavior and dialogue. Specifically these papers contribute to our understanding of the experiences of patients and families as they face the challenging dynamics and complexities of managing chronic conditions including periods of transition and adjustment. The work of O. Mauthner and colleagues highlights the unique experiences and perspectives of heart recipients after transplant. M. Salminen-Tuomaala and colleagues describe the impact of variations in coping resources after myocardial infarction; K. Wickersham and colleagues describe the demanding experience of medication management among women receiving Anastrozole therapy.

In sum, the work included in this issue underscores the variety of challenges patients and families face and the importance of developing innovative interventions to assist and amplify their engagement in self-management behaviors in order to maximize quality of life and positive health outcomes.

*Annette DeVito Dabbs
Mi-Kyung Song
Sabina De Geest
Patricia M. Davidson*

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Research Article

Diabetes Self-Management Education: Miles to Go

**Helen Altman Klein,¹ Sarah M. Jackson,² Kenley Street,²
James C. Whitacre,¹ and Gary Klein¹**

¹ *Division of Research, MacroCognition LLC, P.O. Box 533, Yellow Springs, OH 45387, USA*

² *Department of Psychology, Wright State University, Dayton, OH 45435, USA*

Correspondence should be addressed to Helen Altman Klein; helen@macrocognition.com

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This meta-analysis assessed how successfully Diabetes Self-Management Education (DSME) interventions help people with type 2 diabetes achieve and maintain healthy blood glucose levels. We included 52 DSME programs with 9,631 participants that reported post-intervention A1c levels in randomized controlled trials. The training conditions resulted in significant reductions in A1c levels compared to control conditions. However, the impact of intervention was modest shifting of only 7.23% more participants from diabetic to pre-diabetic or normal status, relative to the control condition. Most intervention participants did not achieve healthy A1c levels. Further, few DSME studies assessed long-term maintenance of A1c gains. Past trends suggest that gains are difficult to sustain over time. Our results suggested that interventions delivered by nurses were more successful than those delivered by non-nursing personnel. We suggest that DSME programs might do better by going beyond procedural interventions. Most DSME programs relied heavily on rules and procedures to guide decisions about diet, exercise, and weight loss. Future DSME may need to include cognitive self-monitoring, diagnosis, and planning skills to help patients detect anomalies, identify possible causes, generate corrective action, and avoid future barriers to maintaining healthy A1c levels. Finally, comprehensive descriptions of DSME programs would advance future efforts.

1. Introduction

Diabetes afflicts approximately 25.8 million people in the United States, or 8.3% of the population. Type 2 diabetes, or non-insulin dependent diabetes mellitus (NIDDM), accounts for 90 to 95% of all diagnosed cases of diabetes in adults [1]. The problem is growing, particularly among young people. Over their lifetime, patients experience increased risks of complications including blindness, kidney damage and failure, cardiovascular disease, nerve damage, and lower-limb amputation. A NIH study from 2011 estimated that costs related to the treatment of diabetes accounts for about \$174 billion of the national health care annually [1].

Type 2 diabetes complications stem from the inability of the body to use insulin properly, resulting in heightened blood glucose levels [2]. This is measured with the HbA1c test, the percent of glycated hemoglobin in the blood. It is commonly called the A1c. The NIH criterion for diagnosing diabetes is an A1c of 6.5 or higher although this varies

somewhat with the individual. Pre-diabetes is between 5.7 and 6.4. A reading below 5.7 is normal [3].

The U.K. Prospective Diabetes Study (UKPDS) [4] found that over a ten-year period, each 1% reduction in A1c (e.g., from 8.5% to 7.5%) was associated with reductions of risk of 21% for death, 14% for myocardial infarctions, and 37% for microvascular complications. They found no threshold value for risk mitigation confirming the value A1c reductions. Research studies, however, rarely follow patients for even a few years so clinical thresholds remain the best assessment of treatment impact.

This research addresses the question of how effectively current DSME interventions help patients with type 2 diabetes achieve sustained control of their blood glucose. Physicians and other health care professionals can prescribe effective medications, provide optimal dietary guidelines, and support needed life style modifications. In the end, however, it is the patient and their caregivers who must make the daily decisions needed to control blood glucose.

There is a wide array of support strategies for patients. Web sites maintained by The National Institute of Health (NIH) [5], the American Diabetes Association (ADA) [6], and the American Association of Diabetes Educators (AADE) [7] provide state-of-the-art recommendations and online support. These include guidelines for food choices and the timing of meals, exercise, and responses to stress and illness. Pharmacology research has produced new and better medications. Human factors practitioners have improved glucose measurement devices [8] and have developed reminder systems to support adherence [9].

With the growing burden of diabetes on health care systems and the plethora of medical, pharmaceutical, and human factors advancements, it is critical that DSME programs increase their effectiveness, sustainability, and scalability. This meta-analysis of interventions started with six reviews of DSME [10–15]. The interventions differed in sponsorship, duration, target group, and educational approach. Three used meta-analyses [10–12]; one adopted a systematic review procedure [13]; one used both meta-analysis and systematic review procedures [14]; and one used a data mining procedure [15]. Each assessed the impact of DSME interventions on glycemic control, a critical barometer of self-management success.

Ellis et al. [10] surveyed 28 studies with a total of 2,439 participants and found A1c reductions of 0.32% for intervention groups compared to control groups. Gary et al. [11] examined 18 studies with a total of 2,720 participants, and found a significant pooled effect size (standardized mean difference) of -0.43 in A1c. Norris et al. [12] examined 31 studies with 4,263 participants, and found an average GHb reduction, a measure related to glycemic control, of 0.76% post intervention.

Ismail et al. [14] reviewed 12 studies with 1,390 participants and reported a pooled standardized difference of -0.32 in the A1c between experimental and control conditions. Sigurdardottir et al. [15] looked at 18 studies with 4,293 participants. They found that only four of the eighteen interventions attained a post-intervention A1c level of 6.4% or less, the boundary between diabetes and pre-diabetes used by some researchers. The current accepted value for healthy A1c is 5.7% or lower.

While these reviews reported modest but statistically significant reductions in A1c levels among intervention participants when compared to control participants, most reductions did not reach healthy A1c levels. Intervention participants remained at risk from elevated blood glucose levels as reflected by A1c or other standards metrics. Finally, Norris et al. [13] provide a classification of 72 studies from 84 articles. Each is described by intervention type and outcome variables. It provides a useful summary of research, but not a quantitative analysis of outcomes.

More disheartening in these reviews, reductions in glycemic control were often not sustained over time. The meta-analysis conducted by Norris et al. [13] illustrates this trend: studies with a post-intervention follow-up period of six months or less showed greater effectiveness in glycemic control than those with longer follow-up periods. Only 12 of the 72 programs reviewed by Norris et al. [13] had follow-ups

of 1 year or later and only two of these found that reductions were maintained. While the later meta-analysis by Norris et al. [12] found a 0.76 reduction in HbA1c from baseline immediately after the intervention, this improvement decreased to 0.26 several months later.

These six overview studies encountered a variety of difficulties and limitations. First, behavioral change techniques have generally lacked standardized definitions and taxonomies [17]. DSME studies in particular do not follow standard routines for delivering care and reporting their results. Further, randomized controlled trials, basic to intervention research, were not universal. Control group treatments were often listed only as “usual care,” with contact times missing in the report [10, 12]. For example, Sigurdardottir et al. [15] report that in at least 7 of the 18 interventions studied, the control groups received more than “standard care” and also showed significant improvements. Ellis et al. [10] also reported that overall control groups showed decreases in A1c levels of 0.66 from baseline at follow-up. Norris et al. [13] found both intervention and control groups exhibited glycemic improvement in 15 of the studies included; in three of these, the control group improved more than the intervention group did. Norris et al. [12] also reported greater improvements in several of their control groups.

Another research problem has been attrition rates. Sarkisian et al. [18] noted high attrition rates in many of their studies, with one reaching 50%. Norris et al. [12] reported that attrition was greater than 20% in one-third of the studies included in their analysis. Norris et al. [13] found studies that reported significant decreases in glycated hemoglobin levels either used very intense interventions or had significantly higher attrition rates. The high attrition rates would skew the outcomes if the least successful patients dropped out. The more of these drop-outs, the better the results would appear even if the DSME program had no real benefit.

Because of these methodological problems, we share Gary et al.'s [11] conclusion that current interventions “yield improvements in glycemic control that are promising, but not yet compelling.” We conducted this meta-analysis to address the problems outlined above. We wanted to minimize the methodological problems identified in the past reviews. Our meta-analysis included DSME research studies from the six previous meta-analysis efforts that provided A1c measures both pre- and post-intervention. We also included later studies to capture more recent DSME projects [16, 19–69]. Studies were included based on their selection criteria and methodological quality as specified below. We excluded studies that only measured A1c less than 13 weeks after the start of the intervention because this interval is too short to reflect A1c changes. Thus, we attempted to compile a set of DSME studies that met more stringent criteria and allowed easier comparisons across studies.

A second reason for our analysis was to provide an initial exploration of the dynamics of self-management. Lippa et al. [70] report that rule-based instructional programs for patients with type 2 diabetes are less likely to be effective because patients often have difficulty applying a large set of rules in complex situations. Similarly, lifestyle self-management interventions for diet, weight loss, and exercise

are notoriously difficult to sustain. Klein and Lippa [71] found that patients leading active lives needed cognitive self-management skills for self-monitoring, including guidance for interpreting their A1c levels and understanding the implications of their data for anticipating, preventing, and repairing problems. This meta-analysis explored current DSME approaches. We were particularly interested in how cognitive self-management versus rules and procedures might impact outcomes.

2. Materials and Methods

2.1. Strategy for Identifying DSME Studies. We reviewed the studies from the six earlier referenced reviews addressing the effect of DSME interventions on blood glucose control [10–15]. We supplemented these with additional studies published from 2005 through 2009 using the same strategies as Ellis et al. [10], Ismail et al. [14], and Sigurdardottir et al. [15]. The selection strategy reflected the standards for articles reporting meta-analyses in psychology [72]. We searched MEDLINE, PsycInfo, and CINAHL for English language publications using the keywords “diabetes mellitus” combined with each of the following: “patient education,” “educational intervention,” “self-management education,” “psychological therapies,” and “clinical trials.”

The titles and abstracts of search results were assessed for relevance and retrieved if appropriate. When the same data were used in multiple publications, we included only one of the publications in our analyses.

2.2. Criteria for Inclusion. All of the studies in our analysis met the following criteria.

- (i) Intervention participants completed a DSME intervention designed to increase adherence and only data collect Per Protocol (PP) was included.
- (ii) Participants were adults with type 2 diabetes as defined by NIH [3]. We excluded people with type 1 diabetes, gestational diabetes, or unspecified type of diabetes.
- (iii) A1c values were available as both baseline and post-intervention measures and data were sufficient to define the means and standard deviations for the A1c.
- (iv) All studies used randomized controlled trials meeting at least one of the following criteria:
 - (1) Random assignment of participants from a single pool (e.g., treatment center, unified recruitment method).
 - (2) Study specified as a randomized trial (unless evidence suggested otherwise, such as significantly different participant baseline characteristics).
 - (3) Study sites were randomly assigned and equivalent (with sufficient evidence).
 - (4) Groups were matched on baseline measures.

2.3. Criteria for Exclusions. A total of 186 unique articles were retrieved. Of these, 134 studies were excluded for the reasons provided in Figure 1. The included studies satisfied the criteria listed above. One study [73] was removed because its Cohen's d was more than three standard deviations above the mean, the cutoff for detecting outliers.

Table 1 describes the 52 studies [16, 19–69], with a total of 9,631 participants included in our analyses. The studies are described by author, publication year, and sample size. Five additional parameters are noted, when available, for each study: the person delivering the intervention, the intervention content, mode of delivery, the treatment duration in weeks, and the time before follow-up in weeks. The variables of intervention profession, content, and delivery mode, are detailed in Table 1.

We classified the content based on the description provided in the program. In some cases, several content areas were mentioned.

Rules and Procedures (RP) was the most commonly mentioned content and focused on explicit guidelines, such as specific rules regarding diet and exercise. An example of a procedure would be how to perform blood glucose monitoring. Rules and procedures can include the use of a journal for recording data but do not typically provide support for translating blood glucose readings into effective decision making.

Affective and Emotion (AE) focused on emotion, motivational encouragement, empowerment, and/or confidence building.

Social and Situational (SS) focused on managing social and situational factors that impede effective diabetes self-management. These strategies might include holiday meal planning and selecting restaurant meals.

Complex Cognition (CC) focused on mental models or other complex cognitive strategies designed to use conceptual understanding of diabetes to moderate blood glucose levels. This goes beyond the simple application of rules and procedures to the use of a mental model to detect anomalies and identify causes, and to generate corrective and preventive strategies.

3. Results

3.1. DSME Effectiveness. The overall results showed that the DSME interventions significantly reduced A1c levels (Table 2). The final mean A1c levels in the intervention group ($M = 7.61$, $SD = 1.34$) were lower than that of the control group ($M = 8.18$, $SD = 1.43$), $t(146) = 3.51$, $P < 0.01$. This is not surprising as studies without intervention effects were less likely to be submitted for publication or to be accepted if submitted. Nevertheless, it is useful to examine the effect size in preparation for more detailed examination of the factors that contributed to these effects.

The overall intervention effect was to reduce mean A1c levels from 8.70% to 7.61%, as shown in Table 2, a reduction of 1.09% that was significant at the 0.01 level. However, the control groups also reduced their A1c levels from 8.70 to 8.18, a reduction of 0.52% that was also significant at the

TABLE 1: Description of included studies and interventions.

	Year	N	Who delivered	Intervention content	Mode of delivery	Duration of intervention in weeks*	Time before follow-up in weeks*
Adolfsson	2007	88	1, 3b	AE, RP	G	30.33	52
Agurs-Collins	1997	55	4, 0	RP, SS	G, I, S	26	0
Amano	2007	39	0	RP	I	13	0
Anderson-Loftin	2005	65	2n, 4	RP, SS	G, S, T	26	0
Arseneau	1994	40	7	RP, SS	I?	0.57	8.67, 21.67
Barnard	2006	99	1, 4, 6	RP	G, I, T	22	0
Brown	2002	224	3c, 4, 6	RP, SS	G, S	52	0
Campbell	1996	200	3c, 4	1: RP. 2: RP, SS. 3: CC, RP, SS.	1: G, I. 2: G, I, S. 3: I, T.	2	11, 24
Cheskin	2008	24	4	RP	G, I	86	0
Christian	2008	273	1, 7	AE, RP	I, TECH	52	0
D'Eramo-Melkus	1992	49	0	Group 1: CC, RP. Group 2: CC, RP.	Group 1: G, I. Group 2: G, I.	12, 18	8, 14
Deakin	2006	291	4	AE, CC	G	6	11.33, 54.67
Engel	2006	50	0	AE	GINS, T, TECH	24	0
Faridi	2008	30	3a, 7	RP	TECH	13	0
Fornos	2006	112	3	RP	I, O	56.33	0
Franz	1995	179	2d	RP	I	6	7, 20
Gabbay	2006	332	3c	CC, RP	I, T, TECH	52	0
Gaede	2001	149	1, 3c, 4	AE, RP, SS	G, I, S	197.6	0
Gallegos	2006	45	3c	RP, SS	G, I, T	50	0
Glasgow	1992	97	4, 5, 6	CC, RP, SS	G	13	0
Glasgow	2000	277	2n, 4, 5, 6, 7	RP	O, T, TECH	26	13
Goudswaard	2004	50	3b	RP	I	26	6, 52
Gucciardi	2007	61	3c, 4, 5	CC, RP, SS	G, I	13	0
Janssen	2009	491	1, 3c	RP?	G, I	52	0
Kim & Jeong	2007	51	3c	RP	I, TECH	26	0
Kim & Song	2008	34	3c	RP	TECH	26	0
Ko	2007	308	1, 2n/d, 4, 5	AE, CC, RP, SS	G, S	0.71	25, 51, 103, 155, 207
Krousel-Wood	2008	76	7	RP	TECH	13	0
Kulzer [†]	2007	181	5	1: AE, CC. 2: AE, CC.	G, C: G, I.	13	0, 52
Ligtenberg	1997	51	1, 4	AE, RP	G, I, T	26	0
Lujan	2007	141	6	AE, RP	G, T	26	0
McKibbin	2006	57	6	AE, RP	G	24	0
Ménard	2005	61	0	RP	I, O, T	52	0, 26
O'Kane	2008	184	3a, 4, 6	RP	G	52	0
Pederson	2007	122	0	RP	I, O	26	0
Pibernik-Okanovic	2004	108	4, 5	AE, CC	G	6	7, 20
Piette	2000	248	3c, 7	RP	T, TECH	52	0
Rachmani	2005	110	0	AE, RP	G	208	0, 208
Rosal	2005	25	3c, 4, 6	CC, RP	G, I	10	3, 16
Schwedes	2002	223	1, 3c, 6	CC, RP	G?, I	24	0
Shea	2007	1355	6, 7	CC, RP	TECH	52	0
Sone	2002	1973	3c	RP	I?, T	156	0

TABLE 1: Continued.

	Year	N	Who delivered	Intervention content	Mode of delivery	Duration of intervention in weeks*	Time before follow-up in weeks*
Steed	2005	106	3b, 4	CC, RP	G	5	0
Sturt	2008	202	3c	AE, CC, RP	I, O, T	12	14
Sun	2008	146	1, 4	RP	GINS	24	0
Trento	1998	96	1, 5	CC, RP, SS	G, S	52	0
Trento	2002	90	1, 6	CC, RP	G, I+	208	0
Tsujiuchi	2002	26	6	AE	G	17.33	0
Uusitupa	1993	82	1, 3b, 3c, 4	RP	G	65	0, 117
Wattana	2007	147	3c	RP	G, I, O	24	0
Yoo	2008	57	3c, 7	AE	G, I, TECH	13	0
Yoon & Kim	2008	51	6, 7	RP	TECH	52	0

Note. *Studies with multiple intervention lengths or multiple follow-ups are indicated by lengths separated by commas; †A1c values not provided in text—values estimated from a bar graph.

Who Delivered: 1 = MD: GPs, or Specialists, 2n = Nurse Certified Diabetes Educator, 2d = Dietician Certified Diabetes Educator, 3a = Nurse Practitioner, 3b = Nurse with Diabetes Specialty, 3c = Nurse (including Nurse Researchers and Educators), 4 = Related Health Professionals: Physical Therapist, Clinical Dietician, 5 = Psycho-social Professionals: Psychologist, Social Worker, Health Counselor, 6 = Other: Professor at Nursing College, Cooking Instructors, Research Assistant, Case Manager, Educationist (MTr), Qi-gong Doctor, 7 = Not a person: Diabetes Manual or Learning-activity-programs, Video, Interactive-telephone-system, 0 = Unlisted, Not Explicit.

Content: AE = Affective/Emotion, CC = Complex Cognitive, RP = Rules/Procedures, SS = Social/Situational, ? = Uncertain.

Mode: G = Group, I = Individual, T = Telephone, S = Social: Family, Spouse, or Friend Attended, I+ = Individual care given if participant needed additional help, TECH = Technology: Cell Phone Text Messages, Internet, Sensor Placement, Computer Registry, O = Other: Community Resources, Pharmacological, GINS = group or individual not specified, ? = Uncertain.

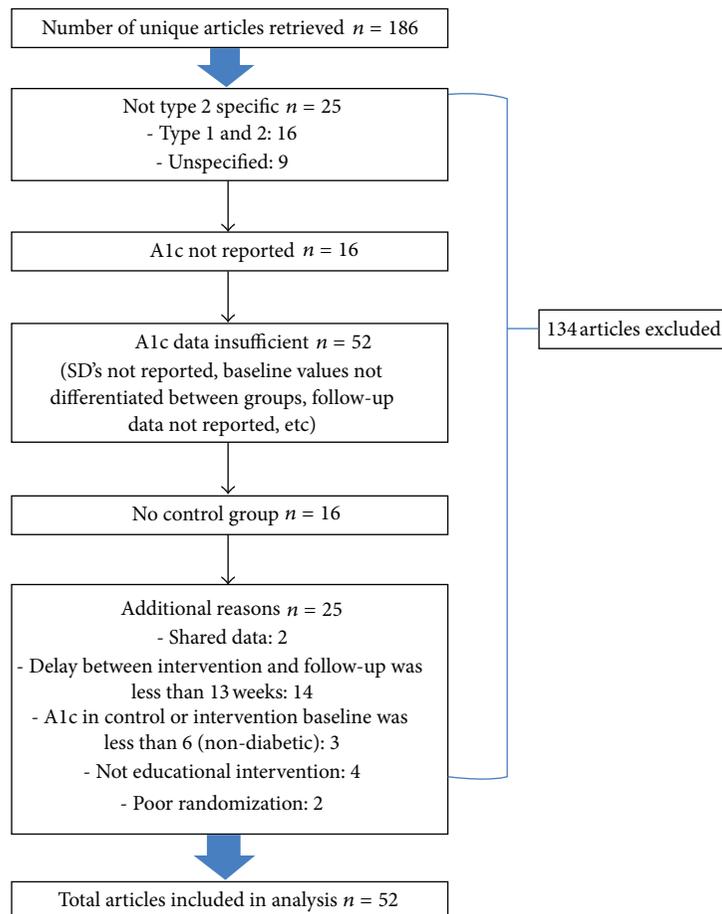


FIGURE 1: Excluded article chart.

TABLE 2: Gain score comparison.

	Baseline mean Alc (SD)	Posttreatment mean Alc (SD)	Alc <i>t</i> -value (within subjects)	Gain score	Est. % below Alc 6.4 at baseline	Est. % below Alc 6.4 posttreatment	% <i>t</i> -value (within subjects)	Impact Score
Control	8.70 (1.48)	8.18 (1.43)	-3.66**	-0.52	11.65%	14.53%	3.15**	2.88
Intervention	8.70 (1.47)	7.61 (1.34)	-8.29**	-1.09	12.73%	22.84%	6.96**	10.11
Significance (between subjects)		$t(146) = 3.51$, $P < 0.01$.		$F(1, 146) = 7.25$, $P < 0.01$				$t(146) = -4.20$, $P < 0.01$.

Note. ** $P < 0.01$. % below Alc 6.4 is an estimate of the percentage of participants in each group who achieved an Alc level below 6.4. Gain Score is Alc change from baseline to posttreatment. Impact Score is the change in estimated percent below Alc 6.4 from baseline to post-intervention.

0.01 level. We used an analysis of variance to compare A1c gain score (post-treatment minus baseline) with treatment (intervention versus control) as the independent variable. The decrease in A1c levels was significantly greater for the intervention condition, $t(146) = 3.51, P < 0.01$.

To put these findings into context, we computed an "Impact Score" reflecting the proportion of participants whose A1c levels were at or below 6.4%. The NIH guidelines set 6.5% A1c as the threshold for diabetes, and so the Impact Score measured the proportion of participants that had moved below this threshold [3]. The Impact Score was computed using reported mean and standard deviation values and does not reflect any departures from normal distributions. We would expect such departures because participants could have extremely high A1c levels, but not extremely low levels. Therefore, the Impact Score is an approximation rather than a true value. In addition, the effect of a program is more than just the participants who reduced A1c below 6.5%. Any participant able to reduce his or her A1c score would have shown some benefit if this reduction was maintained over time. The purpose of the Impact Score is to help capture the accomplishment of the programs.

These caveats aside, the Impact Scores are revealing. The intervention groups had an estimated 22.84% of participants classified as having A1c values below 6.5%. Thus, almost a quarter of the participants who received the interventions would no longer be considered to have type 2 diabetes. However, at the intervention baseline, 12.73% of participants already had A1c values below 6.5%, so the improvement, while statistically significant, was only 10.11% of the participants. That is, 7.23% of the intervention participants who started with A1c scores of 6.5% or greater achieved a safe level of A1c as a result of the intervention, a result that was significant at the 0.01 level.

Further, the control groups also showed a statistically significant improvement of 2.88%. Therefore, the overall treatment impact (difference in Impact Score between control and intervention groups) was 7.23%. An independent-samples t -test revealed that the difference in Impact Scores was significantly greater in the intervention group than the control group, $t(146) = -4.20, P < 0.01$. The long-term clinical impact of the successful 7.23% depends on maintaining the A1c reduction over time. The UKPDS [4] report 10 years to be necessary. We find no data about the intensity of DSME needed to maintain A1c reductions over time.

Finally, we looked at the overall benefit of DSME interventions for participants. Figure 2 displays the final A1c levels for each study included in the meta-analysis. Even though the interventions were statistically significant, most of the studies failed to achieve the healthy blood glucose level of below 5.7 let alone the pre-diabetes blood glucose level of 6.4.

3.2. Intervention Length. Table 3 shows the effects of the duration of the intervention. Longer programs are generally more expensive to conduct and so should result in stronger effects to be considered cost effective. We grouped the studies into three categories: 13 weeks or less, 14–26 weeks, and 27 weeks or more. Each of the three groups showed a statistically

significant lower A1c score for the intervention than for the control. The percent difference between the control and the intervention increased monotonically as intervention length increased. The intervention duration of 14–26 weeks resulted in a stronger effect than those lasting 13 weeks or less. The group with the longest duration (27 week or more), showed the highest percent difference (column 9 in Table 3).

A different picture emerged using the mean weighted d ; the estimated percent below an A1c of 6.5 measure; and the Impact Score. The mean weighted d had a larger value for 14–26 weeks than for 27+ weeks. The estimated percent of participants achieving an A1c below 6.5 as well as the Impact Scores were highest for the 14–26 week group. The three measures all declined from 14–26 weeks to 27+ weeks suggesting little reason to extend interventions. These conclusions are tentative because the 27+ weeks category included two studies with sample sizes over 1,000 that had small individual effect sizes and three studies with very small or negative effect sizes.

An analysis of variance of gain scores (intervention mean minus intervention baseline) by intervention length found significant group differences, $F(2, 71) = 7.60, P < 0.01$. Follow-up analysis using Fisher's LSD indicated that interventions of 13 weeks or less (M difference = $-1.51, SD = 1.44$) had a significantly greater decrease in A1c levels compared to 14–26 week interventions ($M = -0.66, SD = 0.68$) and interventions that lasted 27 weeks or more ($M = -0.56, SD = 0.68$). These results might suggest that, in addition to being less expensive and easier to administer, shorter interventions can be effective in decreasing A1c levels.

3.3. Sustained Effects. Table 4 presents the outcomes for four different delays following the completion of the intervention program: zero delay, 1–13 weeks, 14–26 weeks, and 51+ weeks. None of the studies evaluated A1c between 27 and 51 weeks post-intervention.

Three of these four durations resulted in significant differences between control and intervention conditions. The 1–13 week condition did not. Most of the studies relied on the immediate post-intervention measurement. The 14–26 weeks condition had the greatest percent difference between intervention and control groups, 8.92%, $t(9) = 1.83, P < 0.05$.

The different analyses varied in their conclusions about sustained A1c reductions although none even approached the 10-year retention intervals associated with health indicators. The Impact Score, at the far right of Table 4, indicates that there is little change in impact over the time intervals used. The Impact Scores for zero delay (7.42), 14–26 weeks (7.87), and 51+ weeks (7.22) were similar, with the highest Impact Score occurring in the 14–26 week group. The Impact Score in the 1–13 week group was the lowest (5.49), partly due to the presence of several studies with very little change between the control and intervention groups. The data in Table 4 are reassuring in that the intervention effects did not quickly disappear. The percent difference column for the zero delay (6.29% improvement, control versus intervention group) may indicate that the intervention was not sufficiently long to

TABLE 3: Post-intervention A1c levels.

Length of intervention	N	No. of studies	No. of tests	Control			Intervention			Percent difference	t-value	Mean weighted d	Est. % below A1c 6.4	Control change in est. %	Intervention change in est. %	Impact Score
				A1c	M	SD	A1c	M	SD							
				M	SD	M	SD									
13 weeks or less	5,319	17	32	8.22	1.28	1.29	7.70	1.29	6.40%	2.13*	0.46	15.68%	4.49%	10.58%	6.09	
14-26 weeks	2,247	17	20	8.08	1.58	1.40	7.52	1.40	6.89%	1.84*	0.49	21.19%	1.27%	10.74%	9.47	
27 weeks or more	6,241	19	22	8.20	1.52	1.37	7.56	1.37	7.79%	2.03*	0.23	19.86%	2.02%	8.84%	6.82	

Note. * $P < 0.05$. One article [16] included two intervention groups that were 12 weeks and 18 weeks and is therefore counted twice in the number of studies column. % below A1c 6.4 is an estimate of the percentage of participants in the intervention groups who achieved an A1c level below 6.4. Change in est. % is the change in estimated percentage of participants' baseline to post-treatment. Difference in change in est. % is the difference between the control and intervention groups.

TABLE 4: Mean outcome AIC levels for control and intervention groups, by delay from end of intervention to time of test.

Length of delay	N	No. of studies	No. of tests	Control				Intervention				Percent difference	t-value	Mean weighted <i>d</i>	Est. % below AIC 6.4	Control change in est. %	Intervention change in est. %	Impact Score
				AIC		SD		AIC		SD								
				M	SD	M	SD	M	SD	M	SD							
No delay	8,729	39	43	7.92	1.45	7.42	1.29	6.29%	2.31*	0.29	21.46%	3.16%	10.58%	7.42				
1-13 weeks	1,291	7	9	8.38	1.36	7.66	1.15	8.61%	1.65†	0.12	13.66%	1.89%	7.38%	5.49				
14-26 weeks	1,572	9	11	9.07	1.54	8.26	1.56	8.92%	1.83*	1.02	11.66%	1.08%	8.95%	7.87				
51 weeks or more	2,215	8	11	8.13	1.30	7.65	1.47	5.82%	2.50*	0.32	19.76%	4.41%	11.63%	7.22				

Note. * $P < 0.05$. † $P < 0.10$. % Below AIC 6.4 is an estimate of the percentage of participants in the intervention groups who achieved an AIC level below 6.4. Change in est. % is the change in estimated percentage of participants from baseline to post-treatment. Difference in change in est. % is the difference between the control and intervention groups.

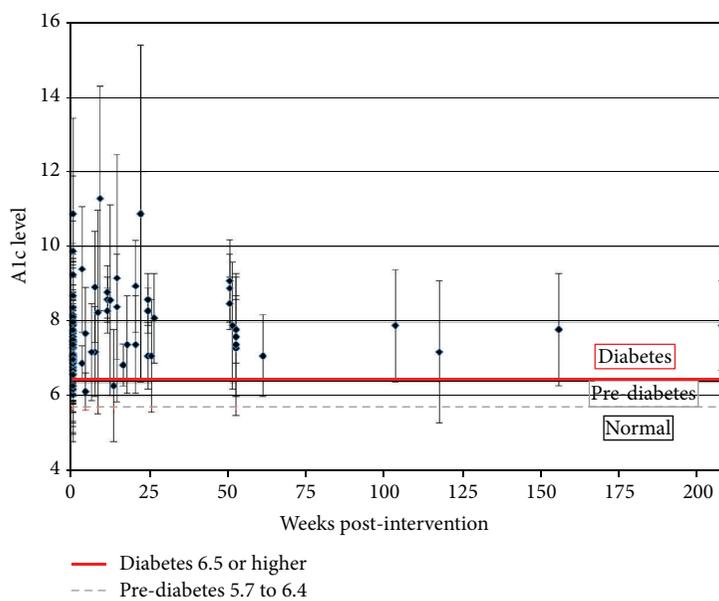


FIGURE 2: Post-intervention A1c levels.

take full effect. The percent difference went up for the 1–13 week (8.61%) and the 14–26 week (8.92%) groups, and then fell substantially in the 51+ week condition (5.82%). The mean weighted d statistic suggests that the 14–26 week group exhibited the strongest effect.

Analysis of variance conducted between intervention and control means revealed a marginally significant difference by duration, $F(3, 70) = 2.21$, $P = 0.09$. Tests that were administered 1–13 weeks post intervention (M difference = -1.06 , $SD = 0.75$) had a significantly greater decrease in A1c levels compared to tests in the no delay group ($M = -0.48$, $SD = 0.50$). Furthermore, gain score analysis using one-way analysis of variance by duration revealed significant differences between groups, $F(3, 70) = 8.97$, $P < 0.001$. Both the 1–13 week group ($M = -1.97$, $SD = 1.70$) and the 14–26 week group ($M = -2.05$, $SD = 1.67$) reported greater decreases in A1c levels compared to the no delay group ($M = -0.64$, $SD = 0.53$), and the 14–26 week group also had a larger decrease in A1c levels compared to the 51-plus week group ($M = -1.16$, $SD = 0.66$). Overall, we found at best weak support for sustained reductions in A1c.

3.4. Intervention Methods. We had planned to compare the effectiveness of different intervention strategies but found that 21 studies of the 52 studies used only rules and procedures. Twenty-nine used rules and procedures in conjunction with one or more of the alternative training methods. In contrast, only one study used Affective/Emotional as a single approach. Complex Cognition was used in conjunction with alternative intervention approaches in 18 studies. Affective and Emotional was used in conjunction with alternative intervention approaches in 16 studies. Social and Situational was used in conjunction with other approaches in 10 studies.

Only 3 of the 52 programs did not rely on rules and procedures, at least in part.

The intervention programs that relied entirely on rules and procedures achieved significant reductions in A1c, from 7.71% in the control group to 7.25% ($P < 0.01$). The groups that blended rules and procedures with other types of methods, or relied completely on alternative methods, also achieved a significant ($P < 0.01$) reduction in A1c, from 8.48% to 7.84%. While this is an initial and tentative assessment of methods, the many studies that used more than one method preclude definitive conclusions about method effectiveness. Further, the descriptions of the intervention approaches were often vague and difficult to classify. The synthesis and application of results from complex interventions require particularly careful identification and documentation [74].

3.4.1. Program Presenter. We examined three classes of intervention presenters: nurse only, nurse in combination with other professional, and no nurse (Table 5). Each was effective in reducing A1c levels, at the $P < 0.05$ levels. The mean weighted d was highest for the nurse in combination with others. The percent difference was highest in this condition (8.54%) while the percent difference was lowest in the no-nurse condition, 6.07%. Analysis of variance conducted on the gain scores (intervention mean minus intervention baseline) by program presenter confirmed significant differences between groups, $F(2, 73) = 7.60$, $P < 0.01$. Follow-up analysis using Fisher's LSD indicated that interventions that used a nurse in combination with some other professional (M difference = -1.84 , $SD = 1.66$) had a significantly greater reduction in A1c levels compared to nurse only studies ($M = -0.77$, $SD = 0.66$) and studies that did not use a nurse ($M = -0.80$, $SD = 0.65$). The results suggest that the addition of

TABLE 5: Mean Outcome A1c levels for control and intervention groups, by type of professional who delivered intervention.

Who delivered intervention	N	No. of studies	No. of tests	Control		Intervention		Percent difference	t-value	Mean weighted <i>d</i>
				A1c		A1c				
				M	SD	M	SD			
Nurse only	2,996	9	10	8.18	1.39	7.58	1.34	7.24%	2.32*	0.17
Nurse in combination with others	3,275	14	21	8.38	1.17	7.67	1.01	8.54%	2.01*	0.59
No nurse	7,536	29	43	8.08	1.57	7.59	1.5	6.07%	2.32*	0.34

Note. * $P < 0.05$.

a nurse along with other educators or health practitioners might increase the effectiveness of DSME interventions.

4. Discussion

4.1. Meta-Analysis Outcomes. The present research looks at the daunting challenge of translating medical evidence about Type 2 diabetes self-management into patient decision making, behavioral change, and ultimately blood glucose control. For people with type 2 diabetes, like those with many other chronic conditions, health care providers can prescribe medications, describe optimal dietary patterns, and outline needed life style modifications, but only the patient can implement these critical recommendations. Because adherence depends on patient decisions, we looked at interventions intended to support adherence. We asked: how well are current educational interventions preparing patients to make effective blood glucose control decisions?

First, the good news. Our meta-analysis showed that intervention groups overall showed moderate reductions in A1c from baseline to post-intervention assessment. The average reduction in A1c for the intervention groups was from 8.70 at baseline to 7.61 at the post intervention assessment. The A1c improvements seem fairly robust, 1.09, but must be interpreted in light of the reductions shown by the control participants. The control participants started at the same baseline of 8.70 and reduced it to 8.18, a modest improvement of 0.52. Both experimental and control groups demonstrated a significant (at the 0.01 level) reduction in A1c.

Improvements in control groups are common and typically attributed to a placebo effect. In the current study, it may also have occurred because some of the studies provided the control group with unspecified “standard training” while the experimental group received innovative training. The intervention group improvement was only 0.57 better than the control group. Nevertheless, it was significantly better ($P < 0.01$). Research suggests that any sustained reduction in HbA1c contributes to patient health [4].

Next, the bad news. According to NIH criteria [3], an A1c of 6.5 separates diabetes from pre-diabetes while 5.7 separates pre-diabetes from normal. This means that current DSME intervention outcomes, while laudable, are far from a healthy level. The intervention conditions resulted in small improvements that were sustained over the span of the include studies.

The Stratton et al. [4] study of long-term effects found that a 1% reduction, maintained over ten years, conferred clear health benefits. Unfortunately, the intervention effects in the present meta-analysis showed some signs of diminishing over even much briefer study durations.

Our findings were more positive than the results of the six previous meta-analyses. Ellis et al. [10] found a reduction of A1c of only 0.32. Gary et al. [11] reported a 0.43 reduction, and Ismail et al. [14] found a 0.32 reduction. We found a reduction of 0.57, compared to the control group.

Nevertheless, the Impact Score (the proportion of intervention group participants who moved from a level of 6.5 or above to a level of 6.4 or below, from baseline to post-intervention, in comparison to the control group) was only 7.23%. This is a small achievement in the face of the resources that went into the interventions. Less than 8% of the intervention participants moved below the line for diabetes, compared to the control group. We recognize that the 6.5 level is somewhat arbitrary, but nonetheless it provides a yardstick for assessing program impact.

In this study, the intervention groups with the shortest durations had significantly greater gain scores. Interventions tended to work at the beginning, but their effects appeared to attenuate over time. This is consistent with Norris et al. [13] that found for studies with follow-ups of a year or more, only two reported sustained A1c reductions. Patients seem to work hard to use rules and procedures at the beginning but have trouble with continued adherence over time. The present meta-analysis seems to replicate greater adherence at the beginning of interventions and later declines.

This study evaluated DSME interventions. While earlier studies sometimes included people with type 1 diabetes, this study was restricted to people with type 2 diabetes. Unlike some earlier studies, the present sample was restricted to studies using randomized trials. Even with better selection criteria, our outcomes were consistent with earlier research: the benefits of DSME were modest [12, 13]. Further, successful programs are often costly, requiring skilled educators, individualized supervision, and extended time commitments from participants. This makes them impractical to scale up.

4.2. Study Limitations. This meta-analysis has several limitations. First, the 52 studies included were all submitted to and accepted by professional journals. Authors are less likely

to submit null findings and editors are less likely to accept them. It is, therefore, likely that our outcomes describe more successful interventions. Second, adherent and successful participants are more likely to complete interventions than are less adherent and unsuccessful participants—the problem of attrition rates. Of the 46 studies that reported beginning and end sample size, 10 studies (22%) had attrition rates greater than 20%. Some of the studies in our sample had very high attrition rates (e.g., greater than 40%). Our outcomes are therefore likely to describe more successful studies and the improvements of more successful participants. Taken together, the outcomes are likely to be biased in support of intervention effectiveness.

4.3. Rethinking DSME Interventions. The 52 studies we reviewed relied primarily on teaching rules and procedures. A total of 21 programs used rules and procedures exclusively. Only three of the programs did not report using rules and procedures. Our findings show that the rules and procedures approach is effective and its effect is sustained, but modest. The gain score in this category was only a 0.46 reduction compared with that of the control group. The interventions that either blended rules and procedures with other methods, or relied on other methods showed larger improvements over the control group, resulting in a reduction of 0.64. The addition of other strategies, such as complex cognitive or affective interventions might, therefore, serve to enhance the effects of rules and procedures-based methods. Despite the improvement in the intervention groups, the final mean values for both of these conditions were still over 7.0 A1c.

The interventions had some effect but the effect was not strong enough to help most people avoid the threat of the damages associated with type 2 diabetes over the long term. When people are first diagnosed with type 2 diabetes, we have to send them home with sample menus and lists of foods to avoid. We have to inform them of the dangers of excessive sugar and carbohydrates. We have to convey the procedures for measuring blood glucose levels. Rules and procedures are necessary, but do not appear to be sufficient.

Lippa et al. [70] conducted Cognitive Task Analysis interviews with people with type 2 diabetes. While rules and procedures were the most common strategy described, this approach is useful but often insufficient. Too often type 2 diabetes patients were burdened with large sets of rules that were poorly understood and difficult to apply. Based on the patterns of successful people, Klein and Lippa [71] concluded that DSME programs should help patients build stronger mental models about the forces they have to juggle—mental models about the tradeoffs between diet, fatigue, exercise, stress, and others. For some, but not all patients, DSME rooted in a cognitive model of system dynamics could supplement the teaching of rules and procedures to help patients with type 2 diabetes become more adaptive and successful. Some patients with type 2 diabetes have used this approach with considerable success.

4.4. Recommendations for Future Studies of DSME Programs. We had difficulty in synthesizing different DSME programs

because of the lack of standard reporting procedures. Often methodologies and intervention descriptions were too brief and ambiguous to see what actions were actually taken. For example, terms such as “diabetes education program” and “healthy lifestyle” were pervasive and often underspecified. These phrases may involve diet and exercise, but the exact type of education is unknown. Future studies should embed curricula in the text or have links to the material online.

Also commonly lacking were indicators of the intensity, mechanisms, and presenters of training. Some studies may have achieved better results because of extensive preparation for the intervention facilitators prior to the interview. For example, in Adolfsson et al. [19], the facilitators simulated being diabetes patients for 2 days in order to understand living with diabetes and then underwent workshop training before interacting with a pilot study group. We could not code facilitator preparation because relevant information was rarely provided. It was not always clear whether interventions were done individually or in a group setting. Studies sometimes blurred the lines between who designed the program and who delivered it. They often neglected to identify who presented the intervention to the participants. These variables however are important and should be included in future research reporting.

Program variables are important in evaluating the cost versus effectiveness trade-off. By giving more attention to clarifying their methods, future DSME programs can help to promote progress and contribute to Evidence-Based Medicine. Abraham and Michie [17] demonstrate that standardized definitions of intervention reporting are feasible. We strongly recommend that future research reports detail behavior change techniques and intervention features. This would support efforts to use research result for program development and would serve as a force multiplier for future meta-analyses [17].

5. Conclusions

The findings reported in this meta-analysis illustrate the positive but modest gains of existing DSME efforts. There are certainly patients who will have difficulty altering long-term behavioral patterns and others who are simply unwilling to try. Nevertheless, innovative DSME programs that build mental models that help people detect anomalies, identify possible causes, and generate corrective actions hold the possibility of moving more participants to healthy A1c levels. We have come a long way and we have miles to go.

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Research Article

Development and Validation of an Online Program for Promoting Self-Management among Korean Patients with Chronic Hepatitis B

Jinhyang Yang

Department of Nursing, College of Medicine, Inje University, 633-165 Gaegum-dong, Busanjin-gu, Busan 614-735, Republic of Korea

Correspondence should be addressed to Jinhyang Yang; jhyang@inje.ac.kr

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The hepatitis B virus is second only to tobacco as a known human carcinogen. However, chronic hepatitis B usually does not produce symptoms and people feel healthy even in the early stages of liver cancer. Therefore, chronically infected people should perceive it as a serious health problem and move on to appropriate health behaviour. The purpose of this paper is to develop and validate an online program for promoting self-management among Korean patients with chronic hepatitis B. The online program was developed using a prototyping approach and system developing life cycle method, evaluated by users for their satisfaction with the website and experts for the quality of the site. To evaluate the application of the online program, knowledge and self-management compliance of the subjects were measured and compared before and after the application of the online program. There were statistically significant increases in knowledge and self-management compliance in the user group. An online program with high accessibility and applicability including information, motivation, and behavior skill factors can promote self-management of the patient with chronic hepatitis B. Findings from this study allow Korean patients with chronic hepatitis B to engage in proactive and effective health management in the community or clinical practice.

1. Introduction

The hepatitis B virus is known as not only the second highest carcinogen after smoking, but also the cause of 75% of primary hepatocellular carcinoma [1]. A carrier of hepatitis B is 30–100 times more likely to have a risk of dying from liver disease than the average person [2]. Approximately 350 million people have hepatitis B worldwide, and, every year, about 620,000 die of liver diseases associated with hepatitis B [3, 4]. Hepatitis B is a disease that is more common in Asians than Westerners. Asian Americans have an infection rate of 5–15%, which is, approximately, more than 20 times higher than the hepatitis B infection rate of the entire population of the US [5]. Korea was ranked 5th in cancer incidence rate in 2010 for liver cancer, and is ranked second in cancer mortality [6]. The prevalence of hepatitis B in Korea was 4.0% of the population over the age of 30 [7]. Likewise, even today, hepatitis B remains a common disease among the average person, but there is a lack of management on disease

monitoring and treatment compliance of hepatitis B virus carriers or patients [8].

Currently, a significant number of hepatitis B patients in Korea are caused by vertical infection from the mother during the perinatal period. Due to the fact that these patients live several years unaware that they are infected, several generations of a family may be affected by hepatitis B, and when they reach the age of 40–50, it is highly likely to progress to liver cirrhosis or liver cancer [9]. Most patients with chronic hepatitis B do not have any specific symptoms until they develop complication and then go through the long-term disease progression period that takes about 10–30 years. It usually goes through the process of immune tolerance, immune clearance, nonreplicative, and reactivation phase. Generally, the targets of treatment are patients with HBeAg-positive infection in immune clearance phase and others with HBeAg-negative infection in reactivation phase. The targets of regular disease monitoring that do not need to receive immediate treatment but must prepare for immune

clearance phase or reactivation phase are hepatitis B virus carriers in the immune clearance and nonreplicative phase [2]. Therefore, there is a need to raise the regular disease monitoring and treatment compliance along with daily life management based on the disease progress and accurate disease knowledge with regard to chronic hepatitis B patients.

According to precedent studies, it was reported that hepatitis B patients have a high level of noncompliance to the regular health checkups or prescriptions [10], have a low quality of life related to health [11], and have a low level of knowledge on disease and disease management, giving rise to deterioration of personal relations or even psychiatric issues such as fear, depression, and anxiety [12]. Furthermore, according to the qualitative research investigating patterns of health care behavior among patients with chronic hepatitis B [13], hepatitis B virus carriers had a low level of disease monitoring through regular medical checkups, and the extent of treatment compliance varied by the pattern of health care in the case of patients subject to treatment. In particular, the treatment compliance in task-oriented type in daily life and body-oriented healthcare type were very low. In addition, most of the hepatitis B patients are not aware of their disease and feel that they are healthy due to the nonvisible and nonspecific characteristics of hepatitis B. Hence, there is a risk of unconsciously spreading the virus to other people [9].

When considering the chronic progress characteristics throughout several decades of hepatitis B, the promotion of patient's self-management ability of chronic hepatitis B is very important. The theoretical frameworks for a program to promote self-management ability of the patients with chronic diseases include knowledge, motivation, and behavior skill factors of disease control [14, 15]. The misunderstanding of hepatitis B patients' regard of the disease often leads to their indifference or inappropriate health behavior [16]. Therefore, it is necessary for health care providers to integrate the existing health care information on hepatitis B to provide accurate knowledge about the health care management of the disease. The motivation factor can be explained as the self-efficacy required for remembering and managing the need and content of disease control or treatment, even if the patient has a good knowledge of it. Behavior skill factors refer to the establishment of action plans and psychosocial management for disease monitoring, treatment compliance, and maintenance of a healthy lifestyle. The patient with chronic hepatitis B should ultimately foster appropriate self-management ability by acquiring accurate and systematic knowledge suitable to oneself, developing motivation through increasing self-efficacy, and pursuing behavioral change through learned skills. The self-management ability has helped patients with chronic disease bring about a result of maintaining and promoting health from the aspect of preventing severe disease and lifelong health management [14].

There must be a premise of an understanding on the fundamental basis of the chronic hepatitis B patients' health behavior to promote their self-management, and health management suitable for an individual's disease progress state, health issues, and health needs must be carried out based on that premise [7]. However, existing studies usually focus on the treatment of chronic hepatitis B itself [17] and

mostly consist of survey on knowledge level [18], survey on infection rate and vaccination rate [19], studies on the correlation between some variables [20], and studies on prevention programs [21]. It is difficult to find studies that have developed and applied a self-care promotion program in consideration of multidimensional factors so that lifelong health management can be internalized. For patients with hepatitis B who have disease characteristics of nonvisible, nonspecific, relapsed and chronic progression, it is viewed that fostering self-management abilities will be effective by acquiring the most suitable information according to a patient's disease progress state and health care behavior through an online program, and by enhancing self-efficacy and the ability to cope through promoting interactions for problem-solving between experts or other patients. Korean patients with chronic disease can easily access online resources for self-management of their own disease due to South Korea's high-speed wireless Internet penetration rate, which is marked at 100 percent [22].

The online program is a system which allows the patient to systematically receive required information with the most updated content through a personal computer without limitation of time and location, to consult one's disease-related health issues with experts, and to be able to foster one's health care ability through various multimedia learning. However, the existing Internet information system mainly consists of content focusing on unidirectional knowledge delivery on the prevention and treatment of hepatitis B and is evaluated as having a lack of utility since it is unable to reflect the reliability assessment of information and user needs [23]. Rather than delivering text-oriented textbook-like content to patients with hepatitis B in various disease progress states, the use of an online program for lifelong health management would be an effective system to consider, which would include an approach of fostering patient's self-management capacities in patient health care by utilizing multimedia and a selective path that is most suitable for disease control, health issues, and health needs of oneself, including one's family.

An online program to promote self-management capacities in patients with chronic hepatitis B can be used to increase the knowledge level on the disease's management and to promote the compliance to overall self-management through enhancing the motivation and behavior skill factors of the patients with chronic hepatitis B. The levels of knowledge and self-management compliance in this study will be measured through self-reporting questionnaires. The compliance to self-management will allow patients to avoid serious consequences such as liver cirrhosis or liver cancer in advance and furthermore will be helpful for the patients to establish a healthy lifestyle from the aspect of lifelong health management. Therefore, the purpose of this study is to develop an online program for patients with chronic hepatitis B to enhance their self-management capacities of the disease, and to evaluate its application.

2. Materials and Methods

A design with a combination of software prototyping approach and system develop life cycle [24] was applied to

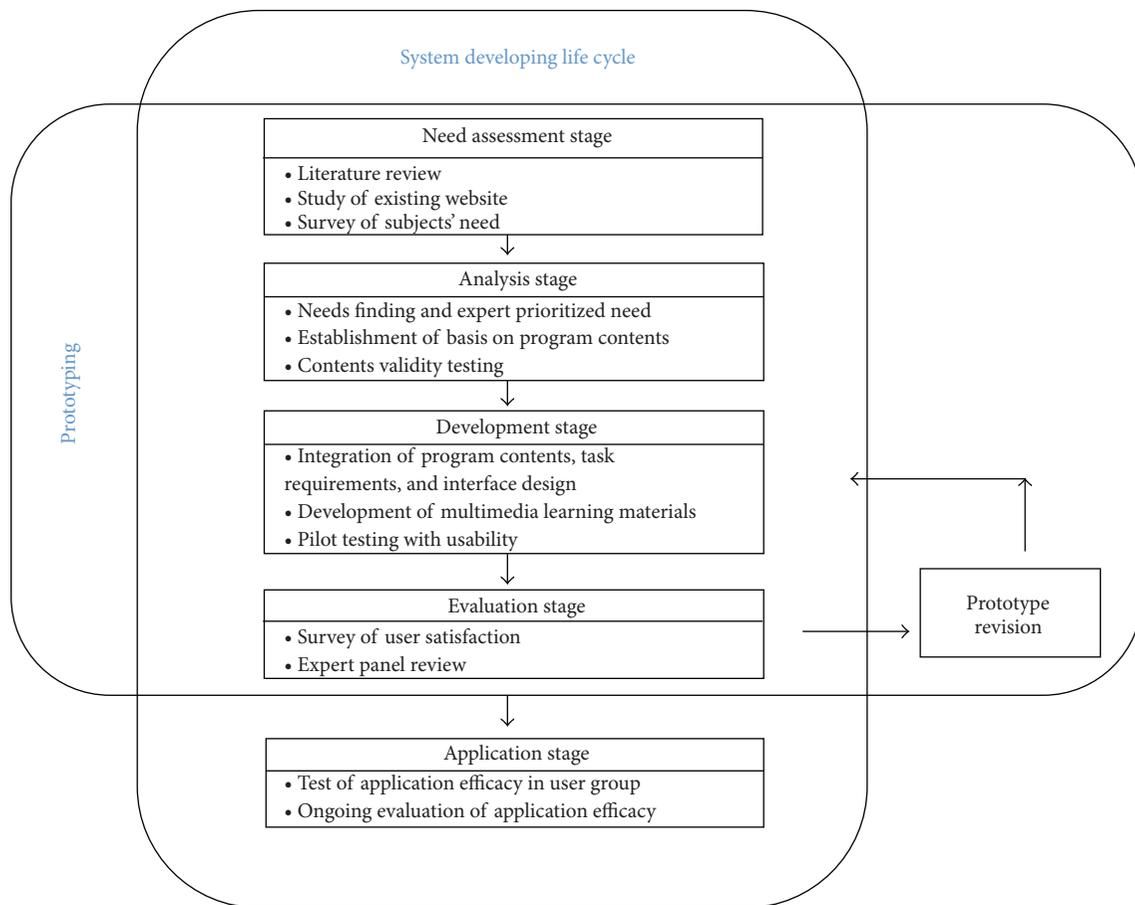


FIGURE 1: Stages for the development of an online program for promoting self-management.

develop an online program for self-management in patients with chronic hepatitis B (Figure 1). After first identifying the user requirements through this design, a prototype online program for promoting self-management was developed and revised by receiving feedback from users and experts. By repeating this process, the image of the actual program was established, its webpage was designed and the program was developed using the traditional system developing life cycle. In this study, the users are those patients who visit a university hospital in which the author is affiliated, who understand the importance of the present study, and who also provided a signed written consent form for their study participation. Since the patient recruitments were made in three different survey periods (need assessment stage, evaluation stage, and application stage), patient participation in each survey period was different from one another. The expert panel was formed by the people who work at the university hospitals where the author is affiliated, and the panel suggests a group of people who specialize in treatment and disease management of hepatitis B, including medical doctors, nurses, and online health program coordinators. All of them were introduced to the present study at an early stage of the study through emails and also signed up for the multiple stage study participation. To protect the rights of those who participated in this study, ethical approval of the study was made by the institutional

review board of the university hospital in which the author is affiliated.

2.1. Need Assessment Stage. The major issues and health issues related to the management of chronic hepatitis B were identified through literature review, websites, patients, and their families. Initially, the contents that are related to self-management of the chronic hepatitis B disease were analyzed by reviewing literature and websites to form questionnaire issues. Through consultations with an expert panel, a questionnaire including 25 items was established. Author and research assistants of this study requested patient participation in the questionnaire survey through face-to-face advertisement of the study to the hospital-visiting chronic hepatitis B outpatients. By recruiting 52 chronic hepatitis B patients and 15 family members of the patients (who signed the written consent form), the program requirements and Internet utilization characteristics were investigated. Also, additional interviews were conducted to confirm the unrecognized or misinformation on the management of chronic hepatitis B.

2.2. Analysis Stage. To analyze the data collected in the first stage, an expert panel was formed consisting of two

physicians, three nurses, and one online health program coordinator, all of whom are involved in the treatment or management of chronic hepatitis B. First of all, major issues and health problems associated with lifelong health management of patients with chronic hepatitis B were uncovered, their priority was then set, and strategies for solving the problems were sought out. Discrepancies were discussed and a consensus was reached. Furthermore, each item related to the program was verified for its content validity by eight other experts among the expert panel pool in this study. Each item was graded on a 4-point scale, where 4 points equate to "Strongly agree" and 1 point equates to "Strongly disagree," and the issues with a minimum content validity index (CVI) of 0.80 were selected. Based upon the analysis results, the foundation of the program contents was established.

2.3. Development Stage. Through this basic process, an online program for lifelong health management with high accessibility and applicability was constructed for promoting self-management of the patient with chronic hepatitis B. This online program broadly consists of 6 main menus: Introduction to Lifelong Management of hepatitis B, What is hepatitis B?, Lifelong Health Management, Management of My Liver Health, Bulletin Board, and Sharing Board, with 24 submenus under them. Apart from this, three menus with much importance and applicability were extracted separately and set vertically on the right hand screen. If the main menu is connected to the information factor, motivation factor, and behavior skill factor, which are the factors to promote self-management in chronic disease patients, the menu "Introduction to Lifelong Management of hepatitis B" was designed as a foundation for strengthening these three factors. The menu, "What is hepatitis B?" is a stage for strengthening disease-related knowledge, which is an information factor. To enhance the learning effect, various audiovisual materials such as PowerPoint presentations, photos, and videos were utilized. The menu "Lifelong Health Management" strengthens the behavior skill factors by assisting in setting specific goals and establishing an action plan. The menu "Management of My Liver Health" strengthens the behavior skill factor by helping the patient understand and implement disease control through pop-up windows or alert messages, as well as individual algorithms. The menu "Bulletin Board" was made to enable viewers to get the latest information. Finally, in "Sharing Board," motivation factors were strengthened through one-on-one consulting with experts and experience sharing with other patients.

Submenus were completed after going through discussions on whether to use images and videos, ways of expressing content, and navigation strategies depending on the topic and content. The developed online program is the uppermost system, which is the initial screen, and is registered at the web address: <http://www.hepb.co.kr/>.

2.4. Evaluation Stage. The developed online program conducted the evaluation on user satisfaction and expert panel review with a survey. The evaluation on user satisfaction used a tool developed by Park et al. [25]. This tool consists of

six questions related to the system (system efficiency, system convenience, design), and 11 questions related to content (content relevancy and content usefulness). Each question is rated on a 5-point scale, with a higher score meaning higher satisfaction. Data collection was carried out with a mail survey, which was enclosed with a questionnaire on 28 outpatients with chronic hepatitis B at a university hospital for approximately four weeks. Participant recruitment was conducted by posting the evaluation participation on the hospital outpatient bulletin board and through face-to-face advertisement of the participation to the hospital-visiting chronic hepatitis B outpatients. Author and research assistant initially explained the method of online program evaluation by phone or by face-to-face meeting to those patients who orally agreed to study participation and sent them written consent forms and questionnaires. After that, the corresponding website address was given and patients were asked to mail their written consent form and the questionnaire to the author after evaluating the program at home using their own computers.

The evaluation of the online program by experts used the health care website evaluation tool developed by Chung & Park [26]. This tool is a 27-question survey consisting of eight areas: purpose, appropriateness, accuracy, credibility, ease of use, interactivity, currency, and authority. Each question is rated on a 5-point scale, with a higher score meaning higher satisfaction. Data collection was carried out by a survey via e-mail attached with a questionnaire by a total of 20 experts consisting of three physicians, 14 nurses, and three online health program coordinators for about four weeks. The author introduced the program evaluation method to those on the expert panel through email and requested response to the questionnaire.

The questionnaire evaluation by users and experts was carried out after receiving written consent on participation in the study after the author and research assistants explained the purpose and method of the study, the spontaneity of participation and withdrawal, and the content of the questionnaire to the subjects. The current online program for promoting self-management was completed after going through numerous revisions through these evaluation results.

2.5. Application Stage. The evaluation on the application efficacy of the online program was conducted on patients with chronic hepatitis B through a survey that measured hepatitis B related knowledge and self-management compliance after using the online program for three weeks. During this period, the author and research assistants checked and encouraged the use of the online program twice a week.

The study was performed by subjecting 42 patients with chronic hepatitis B, who were recruited through the outpatient bulletin board at the university hospital and through face-to-face promotion of the online program during their outpatient visits. The author and research assistants initially explained the method of application evaluation by phone or by face-to-face meeting with participants and received their written consent forms. After that, the participants were asked to respond to a questionnaire survey by mail for pretest

that measured patients' knowledge and self-management performance level in regard to hepatitis B. For those patients who responded to the questionnaire, the website address was given and allowed them to utilize the online program using their own computers for three weeks in their homes. The author and research assistants of the program phoned them more than twice a week to encourage them to use the program continuously and checked for any presence of difficulty in utilizing the program. For those patients who used the program for three weeks, a postquestionnaire was mailed and asked them for response. The collected data was analyzed through paired *t*-test.

The hepatitis-B-related knowledge assessment tool is a questionnaire consisting of 28 questions revised and supplemented by Yang [8] based on 20 questions in the chronic hepatitis B knowledge assessment tool developed by Park [27]. The content of the questions includes overall overview, infection route, understanding of liver function test, symptoms, treatment and management, and vaccination, with each question rated as 0 (incorrect) or 1 (correct) point. Higher score means that the knowledge level is higher. The self-management compliance assessment tool is a set of 15 questions revised and supplemented by Yang [8], based on 13 questions of the health behavior assessment tool for patients with hepatitis B developed by Park [27]. The content of the questions includes the diet, activity/rest, the use of extra-medication therapy, drinking, efforts to acquire health information, prevention of transmission, regular checkup/treatment compliance, and observation of complications/adverse drug events. Each question is rated on a 5-point scale with higher points meaning a higher level of self-management compliance.

3. Results

3.1. Need Assessment and Analysis. To investigate the needs related to the online program for promoting self-management in patients with chronic hepatitis B, data was collected through literature review, existing websites as well as patients, and their families. The main issues were analyzed from the collected data, and its priority and topic for each issue were set by the expert panel. Finally, other experts reviewed its content validity. 10 main issues emerged in total (Table 1).

3.2. Development. The structure of the online program was created by applying relevant theories such as social cognitive behavior theory [28], self-efficacy theory [29], and problem-solving mediation theory [15] on the basis of self-management model theory for chronic disease patients [14]. An online program for promoting self-management was completed to implement the online system using various strategies that can enhance accessibility and applicability. All content was provided by synchronizing voice, video, and text data to arouse the subject's interest and enhance the educational effect.

Once you enter the website through the initial screen, it was designed so that the entire menu of the online

program can be viewed at a glance (Figure 2). The structure of the online program is consisted of six main menus with submenus and three additional menus (Figure 3). First, "Introduction to Lifelong Management of Hepatitis B" explains why hepatitis B must be managed from the aspect of lifelong health management, and it introduces the overall orientation of the program and the expert panel. Second, in "What is Hepatitis B?," after writing the actual situation for each issue regarding the 10 main issues with storytelling, the reply to each situation was provided by making educational material using multimedia. The subjects were made to be able to foster their self-management ability through web-based learning utilizing various multimedia materials. Third, "Lifelong Health Management" consists of a guide to four submenus. If subcategories of each guide are examined, daily life guide includes diet, exercise, personal hygiene, and regular checkup; medication guide contains safety precautions upon taking medication, type of medication, and insurance benefit; guide to hepatitis B prevention has infection route, vaccination, vertical transmission prevention, and management during pregnancy and breast feeding; sociopsychological guide covers employment and enlisting in the military, social prejudice, and stress and anxiety control. Fourth, "Management of My Liver Health" consists of four submenus. The subjects can identify their own level of knowledge through a quiz and be provided with feedback on how to cope appropriately through an individual algorithm based on the data they have entered. This data is stored as a database and was made to be utilized in future research. The subjects can check their learning progress. In addition, once one's checkup results, regular checkup date, and taken medication are entered into "My Liver Health Diary," it reminds him of the next checkup date through a pop-up window each time the website is accessed and re informs him the meaning of the checkup results, importance, and precautions to take in case of complying to the taken medication. In "My Infection Monitoring," it enables a subject to identify the current stage of one's hepatitis B infection using an individual algorithm and specifically explains what kind of management is needed. Fifth, "Bulletin Board" includes hepatitis-B-related articles, press release materials, and announcements and allows the user to view the latest information and use it for help. Lastly, "Sharing Board" is comprised of three submenus. FAQ was created by preparing replies based on the details frequently asked by patients with chronic hepatitis B and their families. One-on-one consulting was made to raise the subject's level of satisfaction and have them practice health behavior more actively through interactions with experts. Testimonials were designed to allow subjects to interact with other patients and their families, and have them form and vitalize self-help groups while sharing each other's experiences.

Besides this, three separate menus in addition to the main menu, with contents of much importance and applicability, were designed horizontally on the right hand side. "Treatment Guidelines" suggest standards of beginning treatment, treatment, safety precautions upon treatment, disease monitoring, and standard of finishing treatment. The glossary was designed to instantly provide a description once a patient or his family clicks on a word hyperlinked to a terminology that

TABLE 1: Main issues of program for promoting self-management of patients with hepatitis B.

Priority	Main issues	Topics
1	“Hepatitis B, is this genetic disease?”	(i) Definition of hepatitis B (ii) Infection route of hepatitis B
2	“I am healthy!”	(i) Natural course of hepatitis B (ii) Sign and symptom of hepatitis B (iii) Importance of disease monitoring
3	“I don’t exactly know what GPT is”	Understanding of the results of the test
4	“When do I have to take this medicine?”	(i) Indication of treatment (ii) Importance of compliance with medication
5	“Level of liver function test went up again in spite of medication for a long time.”	(i) Drug tolerance and side effect (ii) Management of drug tolerance and side effect
6	“Do I have to quit drinking or smoking?”	Management of daily life
7	“Am I a hepatitis B carrier? I got a vaccination against hepatitis B a long time ago”	Vaccine candidates
8	“How do I have to manage not to infect my baby?” “Could I perform breast feeding for my baby?”	(i) Prevention of vertical infection with hepatitis B (ii) Breast feeding
9	“I don’t want others notice that I have hepatitis B,”	Psychosocial coping
10	“I’m worrying about getting liver cancer eventually.”	Stress management

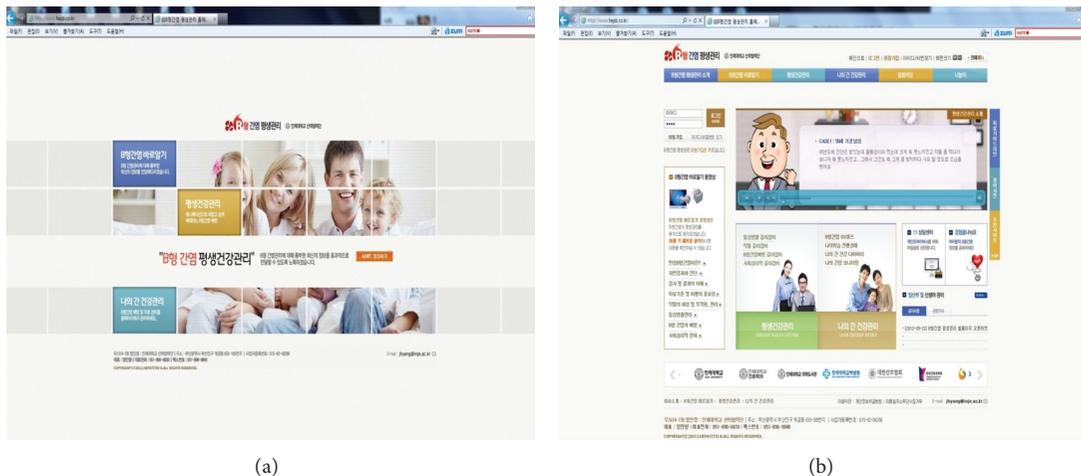


FIGURE 2: Initial screen and main page.

is difficult to understand. “Recommended Websites” allows patients to conveniently obtain support by providing links to various Korean websites such as hepatitis-B-related societies, government institutions, and social support networks in Korea.

3.3. Program Evaluation. The evaluation of the online program established in this study was carried out through an evaluation conducted by an expert panel involved in the treatment and health management of patients with chronic hepatitis B, and user satisfaction of patients with chronic hepatitis B. First, as a result of analyzing the responses from 28 respondents who voluntarily participated in the program,

user satisfaction evaluation among outpatients with chronic hepatitis B turned out high in the order of 4.01 points for contents usefulness, 3.85 points for contents relevancy, 3.82 points for design, 3.75 points for system convenience, and 3.68 points for system efficiency out of a perfect score of 5 (Table 2).

As a result of analyzing the responses from 17 health professionals comprised of physicians and nurses who engage in treatment or management of patients with hepatitis B and three medical informatics experts, purpose had 4.35 points, appropriateness 4.22 points, ease of use 4.14 points, and credibility 4.07 points, which were higher than other criteria; currency had the lowest score of 3.54 points (Table 3). For

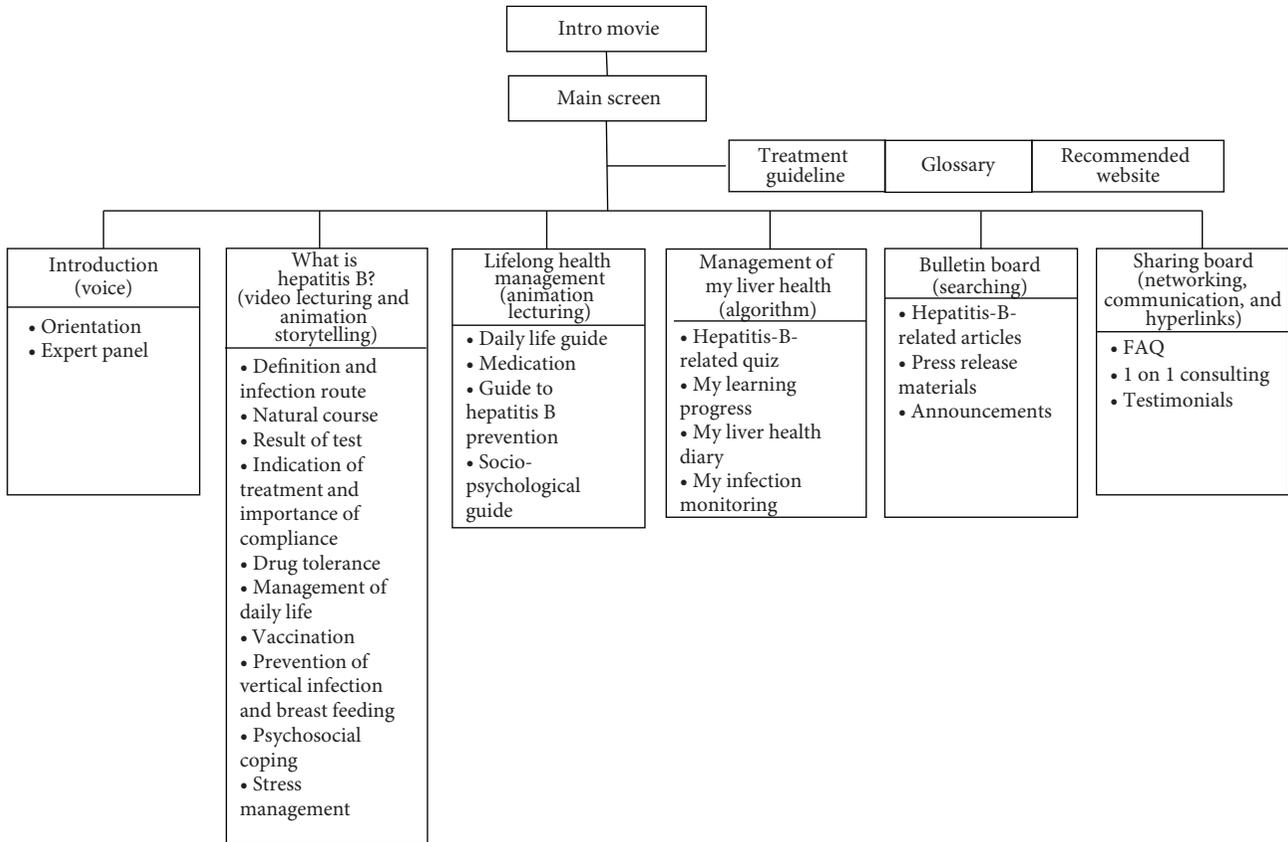


FIGURE 3: Structure of the online program.

each item, while purpose, site map, site title, and relevant content of the online program had high scores, the date of last modification, user feedback mechanism, authors of all information, and validation process had relatively low scores. Therefore, these were supplemented in the prototype revision process.

3.4. Application Evaluation. After recruiting 42 patients with hepatitis B through one-on-one promotion at the outpatient clinic and the hospital outpatient bulletin board to evaluate the application of the online program developed in this study, an analysis was conducted on the knowledge and self-management compliance related to hepatitis B to test the effect before and after application (Table 4). As a result of analyzing the differences of the knowledge and self-management compliance between before and after the application of the online program, significant differences were evident. According to analysis by item, in the case of knowledge related to hepatitis B, the correct answer rate of “If my level of liver enzyme is normal, I do not have to do my regular checkup,” and “If my level of liver enzyme reduces to normal levels, I can stop taking medication” significantly increased. In the case of self-management compliance, the level of compliance significantly increased in the items “I do not use nutritional supplements or folk therapy on my own discretion” or “I regularly do my checkup or take my medications as prescribed.”

4. Discussions

As a result of analyzing domestic online systems operated under the topic of “hepatitis B,” a significant number of websites were found to exist to advertise pharmaceutical companies or primary clinics. Most of the information was focused on pathological anatomy and the disease itself, which provided excessively professional or overly superficial information. In cases overseas, there were many websites related to management of hepatitis B, which tend to be more specialized and subdivided than in Korea. However, most of these websites were focused on unidirectional knowledge transfer on disease prevention and management of hepatitis B [7].

It is considered that the management of chronic disease is effective when a program for promoting self-management is carried out in consideration of multidimensional factors, rather than knowledge-oriented education to allow proper health behavior to be internalized from the aspect of lifelong health management, along with specific disease management behavior. To patients with chronic hepatitis B, internalization of continuous disease monitoring, treatment compliance, and proper health behavior are important above everything else [17]. However, precedent studies pointed out the fact that it is difficult to hear what the major concern of patients was because caregivers provide consultation focusing on virus infection to patients with chronic hepatitis [12] and the

TABLE 2: User satisfaction with online program for hepatitis B patients ($n = 28$).

Criteria	Category	Mean score	Mean score of each criteria		
System efficiency	Easy to connect	3.73	3.68		
	Fast to search information	3.64			
	Easy to contact to operator	3.58			
System convenience	Easy to use the system	3.92	3.75		
	Friendly to use	3.75			
Design	Attractive design	3.82	3.82		
	Well-arranged information	3.82			
	Up-to-date information	3.79			
	Clear information	3.75			
	Content relevancy	Necessary information		3.85	3.85
		Reliable information		3.88	
		Accurate content		4.02	
Rich content		4.05			
Content usefulness	Detailed content	3.64	4.01		
	Content related to me	4.14			
	Useful for my health behavior	3.92			
	Easy to understand	3.96			

primary care physician's management of chronic hepatitis B remains at a level of passive disease monitoring since it mainly focuses on test results [30]. It can be seen that the subjects who have applied the online program for promoting self-management developed by this study were helpful in promoting the self-management of patients with chronic hepatitis B by significantly increasing the level of disease-related knowledge and self-management compliance, compared to the instance before application.

As a consequence of additionally analyzing the subject's disease-related knowledge prior to applying this online program, with regard to questions with incorrect answers at a correct answer rate below 50%, it implied that there is a problem in disease control since patients had an inaccurate knowledge of details. For example, "If my level of liver enzyme is normal, I do not have to do my regular checkup," and "If my level of liver enzyme goes down to normal levels, I can stop taking medication" is essential knowledge in managing chronic hepatitis B. Many hepatitis B virus carriers' inadequate understanding of the disease resulted in indifferent or inappropriate health-seeking behavior towards their disease management [31]. Additionally, the level of hepatitis-B-related health behavior was significantly higher in subjects with a high level of knowledge on hepatitis B [32]. One qualitative study [33] pointed out that patients with chronic hepatitis B appeared to be unable to hear sufficient explanation on their infectious status and future disease control from caregivers at the initial diagnosis and emphasized

that the patients must have adequate guidance and education so that they can have an accurate understanding of their infectious status and better manage their disease in the future.

As a result of additionally analyzing the self-management compliance of subjects before the application of the online program, items below the average rating of 3.5 points included "I do not use nutritional supplements or folk therapy on my own discretion," and "I regularly do my checkup or take my medications as prescribed." Especially, regular checkups or steady intake of medication are essential items for preventing liver cirrhosis or liver cancer and, ideally, should be a perfect score of 5 points. This lack of compliance, however, is believed to be due to the disease characteristics of chronic hepatitis B, which attack without specific symptoms and progress for a prolonged period [13]. Therefore, it is necessary for nurses to provide guidance to the subjects to have an accurate understanding of their health conditions and disease-related knowledge and take the initiative in practicing health management by adequately applying this program in nursing practice.

5. Conclusions

The ultimate aim of the online program for promoting self-management is to prevent severe liver diseases such as liver cancer beforehand and, furthermore, establish a healthy lifestyle from the aspect of lifelong health management by raising the subject's awareness on the importance of hepatitis B infection management while promoting regular disease monitoring, treatment, and health management compliance. In order to achieve this objective, it is of paramount importance for the patient to understand the characteristic of their disease and promote self-management ability against chronic diseases.

In the case of the online program, a lifelong health management support system, taking on the approach of fostering problem solving and self-management ability to patients with hepatitis B with various disease progress statuses will be more effective. This online program enhances the effectiveness of self-management with the latest updates through a tailored approach using an individual algorithm without limitation in time and space, web-based interactive learning, consulting with experts, vitalization of self-help group with other patients, and virtual situations and various multimedia materials. Therefore, there is significance in that this research finding allows patients with chronic hepatitis B to engage in proactive and effective health management when applying such online programs for promoting self-management in the community or clinical practice.

Limitations

Several limitations have been identified in this study. First, this study was conducted at one university hospital, making generalization of results to other populations unknown. Therefore, further multisite study is needed. Second, the application evaluation of the online program developed in the study was conducted by one group pre-post test design

TABLE 3: Online program evaluation by expert panel ($n = 20$).

Criteria	Item	Mean score	Mean score of each criteria
Purpose	Purpose described	4.58	4.35
	Intended audience described	4.52	
	Sufficient information provided	4.34	
	Consistent content organization	3.98	
Appropriateness	Appropriate site title	4.15	4.22
	Relevant content for the purpose	4.25	
	Relevant content to intended audience	4.20	
	Relevant content for a subject	4.37	
	Appropriate information presentation	4.28	
	Relevant linkage	4.33	
Accuracy	Understandable content to intended audience	3.94	3.92
	Accurate information	3.96	
	Source of the information	4.28	
	Responsiveness	3.88	
Credibility	Validation process described	3.57	4.07
	Organization behind the site clearly presented	3.78	
	Organization address, phone, email	4.36	
Ease of use	Site map	4.24	4.14
	Structure of the site clearly communicated	4.11	
	Search function	4.08	
Interactivity	Clear user feedback mechanisms	3.52	3.73
	Care of users' feedback	3.95	
Currency	Easy to access	4.08	3.54
	Date of first posting	3.32	
	Date of last modification	3.21	
Authority	Authors of all information	3.56	3.83
	Authors' name and affiliation	4.10	

TABLE 4: Comparison of knowledge and self-management compliance before and after application of the online program ($n = 42$).

Variables	Before		After		t	P
	Mean	SD	Mean	SD		
Knowledge	17.33	4.13	18.75	3.99	-2.45	.019
Self-management compliance	59.02	7.11	60.59	7.82	-2.30	.027

with small sample size. To further improve the reliability for the efficacy evaluation of this program, there is a need for a randomized controlled trial, pre-post test design, and a more sufficient sample size. Finally, since this online program is only subjected to Korean patients suffering from chronic hepatitis B, it will be limited to foreign hepatitis B patients using different languages other than Korean.

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Research Article

A Web-Based Programme for Person-Centred Learning and Support Designed for Preschool Children with Long-Term Illness: A Pilot Study of a New Intervention

Anna-Lena Hellström,^{1,2,3} Agneta Simeonsdotter Svensson,^{1,3,4}
Ingrid Pramling Samuelsson,^{1,3,4} and Margaretha Jenholt Nolbris^{1,2,3}

¹Institute of Health and Care Sciences, The Sahlgrenska Academy, University of Gothenburg, P.O. Box 457, 405 30 Gothenburg, Sweden

²Urotherapy Department, Queen Silvia Children's Hospital, 416 85 Gothenburg, Sweden

³Centre for Person-Centred Care (GPCC), University of Gothenburg, P.O. Box 100, 405 30 Gothenburg, Sweden

⁴Department of Education Communication and Learning, University of Gothenburg, P.O. Box 300, 405 30 Gothenburg, Sweden

Correspondence should be addressed to Anna-Lena Hellström, annalena.hellstrom@fhs.gu.se

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For children living with long-term illness, school age is a risk period with regard to psychosocial ill health and poor compliance with treatment. There is a need for methods to promote health, well-being, and self-esteem. This study describes a new concept for supporting children, person-centred web-based learning and support, which has been tested in 12 preschool children and incorporates learning about feelings, relationships, and the right to integrity. SKYPE was used for conversations between the child and the web teacher. *Methods.* The programme was developed and tested in two steps. The conversations were tape-recorded and analysed using phenomenography. The questions addressed concerned the quality of the intervention process: accessibility of intervention, learning content and support, and identification of measurable items and patterns. *Findings.* The children found it interesting to communicate with their web teacher using SKYPE. The story about Max and Sara served as a good basis for discussion, and development was found in the learning process. The children were able to talk about relations and feelings and developed an understanding for use in new situations in their daily lives. Items and patterns that are useful for research and documentation were identified, for example, well-being, resources, needs, and wishes.

1. Introduction

Children living with a long-term illness are used to facing problems. The child's family contributes to a feeling of safety and comfort for the child [1]. However, when the child starts school, the parents are not there, and friends and peer groups start to become important to the child, and a feeling of not being like others often arises [1–4]. School age is a risk period with regard to psychosocial ill health and poor compliance with treatment [5–7]. Despite efforts to support children when they face these problems, they are not enough and we need to find new methods of prevention and strengthen the children to feel that they are good enough in order to avoid these situations, given the negative consequences for health.

The purpose of the project is to strengthen the child's own resources, self-esteem, and process of learning via a web-based programme.

Young families are occupied with jobs, school, and leisure activities and do not like to spend too much time at hospitals. Receiving information, being together on the Internet and using a computer program, can today be considered a tool to satisfy the needs of patients and their families for support in daily life. Children and adolescents have good skills in Internet-based technology according to a review investigation [8]. In the field of paediatric/adolescent oncology, this has been tried to manage stress and ill health [9]. Eighteen-year-olds with leukaemia took part in a randomized study to evaluate an interactive programme through which symptoms

and signs of ill health could be communicated. In one group that had access to the programme many questions and problems could be resolved at an early stage. In another computer-based study, participatory design has been used to support seriously ill children [10]. The children, aged nine to eleven years, participated with useful ideas during the design process. A new challenge is to design a programme that can be used by children who cannot read or write. Web-based learning and support for preschool children is a new field that needs study.

An overall aim of the project is to develop a user-friendly, quality-assured web-based person-centred model for learning and support that can be used in different paediatric long-term or chronic illnesses. The aim of this specific paper is to describe the intervention tested in a pilot study. The questions addressed concern the quality of the intervention process in terms of accessibility, relevant learning content and support, and identification of measurable items and patterns useful for person-centred learning and support.

2. Theoretical Background, Statement and Intervention

2.1. Theoretical Background, and Statement. To focus on the child and the child's resources and needs, the model of person-centred care (PCC) is used [11–13]. PCC is explained as focusing on the person and not the illness, and on the patient's experience of his or her situation. The purpose is to understand behaviour and symptoms from the perspective of the individual patient and to make caring support and treatment fit the person's need. To manage this, it is necessary to proceed from knowledge of daily life and priorities of the child with a long-term illness. For each child, resources and needs are being identified and focused on [13]. The project sheds light on health, which is here considered to be related to the individual. Antonovsky's salutogenic model [14] postulates factors contributing to the maintenance of health and well-being. Regarding health as a point on a health ease/dis-ease continuum and movement towards the health end are important. The child's capacity to stay well and even improve health in difficult situations could be based on three factors: (1) comprehensibility, a combination of the ability to assess and understand their situation, (2): (a) meaningfulness, finding meaning to ability to assess and understand their situation, (b) meaningfulness, finding meaning to moving in a health-promoting direction, and (3): manageability, the capability to do so. In the present study, health equates to well-being.

In order to study the process of learning and how it occurs, the variation theory by Marton and Pong will be used as a basis [15]. This theory has its origins in phenomenography, which studies relations between individuals and what will be learned. This theory points out a need for variation in perception of different aspects of a phenomenon. By discerning different aspects of the studied phenomenon, it can be experienced and ultimately understood by the child. Samuelsson and Carlsson [16] have focused on preschool and educational development in their research, with the

aim of getting the child to think about, reflect on, and communicate his or her thoughts. Three levels are described. Level 1 signifies that the child's perception of the variations in the teaching is identified and reflected. In level 2, general structures become observable, and in level 3 there is a perception of the child's own learning, what, how, and why the child acts in a certain way and how he or she could act differently.

Learning is a central aspect of the study, and the starting point is the child's perspective and experience. The focus is on how the child perceives the content and various objects of learning within it, that is, the meaning that the child constructs for it. For example, when a new theme is introduced in the web programme, it has to be raised and highlighted [17]. In the present study, a pedagogic approach is used to support health and well-being, which may be related to the way the child experiences the problem that he or she deals with in life. The way the child communicates his or her perception/experience is important to the process of learning and the evaluation of the study. The child's perception of different parts of health and well-being can be communicated between the child and the web teacher (here the researcher) to illuminate a variation in the way the content is perceived. This approach to learning is called the development pedagogic and is linked to variation theory adjusted to preschool children [16]. In preschool educational research, it is important to relate playing and learning to each other. Furthermore, playing is a tool for children in communication and cooperation with other children and adults. When playing, the child develops social competence, which is important to the ability to compromise and feel sympathy and empathy [17]. In this project, playing is regarded as an instrument to obtain reflective knowledge [16, 17].

2.2. Intervention. The intervention is designed like a virtual preschool for children of four to six years of age and is developed for use on a website platform and SKYPE. This service allows users to communicate by web camera over the Internet. The teaching is built on pictures developed for this project from "see, hear, and do" cartoons used for children with cancer [18]. The child receives the necessary equipment to communicate, a tablet computer, and SKYPE, together with printouts of the pictures.

The programme starts with an introduction and face-to-face supervision between the researcher/web teacher and the child, which also provides an opportunity for the child and the web teacher to get to know each other. This procedure helps to overcome cognitive, psychosocial, and language barriers. The children are encouraged to use the programme whenever they wish between the predetermined followups each month. Useful information for parents about communication is accessible on the platform.

On the platform, the preschool web library presents the different sections. There are instructions (a voice talking), sounds, and pictures illustrating different actions. The main topics are relations, feelings, the right of integrity, body function, and basic preschool knowledge. The first section used from the web library is called Max and Sara's families.

Max and Sara are the children in the story (Figure 1). In this section, a common range of family constructions is introduced (Figure 2). The purpose of these pictures is to understand the family relation, in general and for the individual, and its meaning/roles. Exercises using numbers, letters, prepositions, and colours are also included. A web teacher instruction is included to guide the teacher to achieve the aim of particular pictures. After the presentation, the first question to discuss could be “how about your family? How many people are in your family?” Depending on the answer, the conversation should develop to achieve the above aim. Resources and needs are identified, and the teacher concentrates on the needs and strengthens the resources.

The second section, called Max and Sara’s preschool, is about the preschool setting and relations outside the family (Figure 3), but content from the first section is still involved and practised if necessary. The purpose of the second section is to understand relations outside the family and their meaning/roles, friendship/friends, and learning/teacher. Another purpose is to get meanings and words for emotions and learn to understand feelings like happiness, fear, and anger. What they feel like and how to recognize different feelings in other people are discussed as are different reasons for feeling like that (Figure 4).

a/How to make friends and social rules are discussed; b/fun things I do/I want to do; c/tedious things; d/paint how it feels when you are angry, sad, happy; g/how does it feel; h/what do you think you can do; i/is it good to show what you feel; j/stories that describe feelings are discussed; k/integrity and the right to say stop are discussed.

The third section is about the human body. The purpose of this section is to obtain knowledge about the function of the body and reinforce what is healthy. We also discuss what can go wrong, illness and how to treat or compensate for it. This section was not included in the present pilot study.

The teaching method at the web preschool may vary and, in addition to pictures, there can be quizzes, film sequences, songs, and fairy tales. The design of the platform aims to be attractive and to strengthen health and the child’s own resources and to cater to the child’s joy of playing. In the pilot study, we mainly used the pictures.

3. Methods

3.1. Participants and Process. The intervention was pilot tested in two parts in order to ensure the quality of the web preschool before a larger study could be conducted. The first test involved healthy children, three in home settings, and four in a preschool setting. Altogether, seven children, aged three to six years, participated: six boys and one girl. After an introduction, the children took part in the intervention, and the conversation between the web teacher and the child was observed and notes were taken. Between each intervention, the programme was improved and updated according to the results.

The second test included five children with recurrent urinary tract problems. All of them were girls aged between four and six years. This time the intervention was tested



FIGURE 1: Max and Sara, the children in the intervention. Illustrations by Gunilla Wårnström.



FIGURE 2: Sara’s second family. Illustrations by Gunilla Wårnström.

on the web using SKYPE. This means that the conversation between the child and the web teacher was conducted using a web camera and the Internet.

The introduction was conducted and followed the described intervention. Follow-up conversations on the web platform according to the programme were performed after one and two months. The conversations were tape-recorded and transcribed verbatim.

The child was encouraged to consider different phenomena in each theme and picture concerning his or her situation and experiences in daily life [16]. The web teacher offered enough time for the child to think about and reflect what happened, what they did, how and why they did so, and what they could do, and furthermore what they wished could happen. The conversation between the child and the web teacher included open questions related to the aim of each part of the intervention. After the introduction, questions could be raised such as: What do you think? Do you recognize this? what is it like in your family (or at preschool)? Tell me! How would you like it to be? Why do you think it is like that? What could you (or Sara, Max) do to feel better? In this second test, the conversation continued and developed following the themes and what was discussed before.

After the last intervention, at two months, interviews with the parents were also conducted using short open questions on what they thought about the intervention,

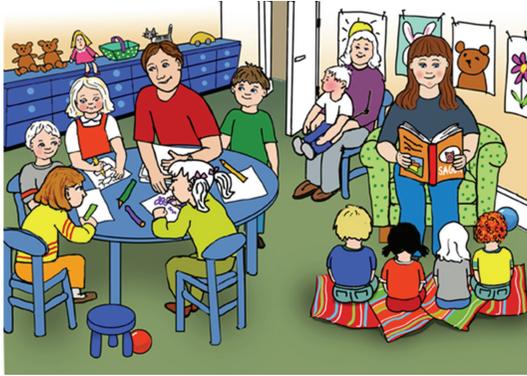


FIGURE 3: At preschool. Illustrations by Gunilla Wårnström.



FIGURE 4: Sara feels ill and has to stay in bed. Illustrations by Gunilla Wårnström.

such as accessibility, content, and their child's interest. These answers were used to support the findings from the child-web teacher conversation.

3.2. Analysis and Method. The quality of the intervention process was investigated by analysing the conversation between the child and web teacher in addition to the interviews with the parents. Relevant content in learning and support was investigated by analysing the text. Measurable items and patterns were identified, considering accessibility, person-centring, health, and learning.

The method chosen for the analysis was phenomenography [15]. The transcribed text from conversations and interviews was read carefully by the authors. The interpretation from the entirety to the parts was conducted in order to increase understanding of the text. Throughout the process, the parts of the text were first analysed independently by the authors for agreement and then the categories were checked for content to increase the trustworthiness of the analysis. The children's and parents' statements were identified and discriminated. The entirety and the parts were met and the dependency between them was seen to answer the aim of the study. Room for the outcomes was created for categories describing the responder's different ways of apprehending/experiencing the phenomenon. Similarities in understanding constituted one category. In the present study,

two main categories were generated: consequences of playing and consequences of experiences. Each main category consisted of two subcategories: "the child's participation in playing at preschool" and "the child's participation in playing in the family and among friends," and "feelings related to preschool" and "feelings related to the family." The criteria for a category were fulfilled according to the method: to have a relation to the phenomenon, a logical relation between categories and as few categories as possible to find the critical variation in data [15]. Representative quotes of statements by the children supported the meaning of the categories and increased trustworthiness. The interviews with the parents, with a few short open questions, were analysed and sorted according to their experience of the intervention, in terms of accessibility, relevant content, and their child's interest.

3.3. Ethical Consideration. Informed consent was obtained from the children and the parents. The children and their families were informed that they could interrupt their participation at any time. Confidentiality was ensured. The Regional Ethical Committee for research has approved the project.

4. Results and Discussion

This section describes findings from the web intervention as a method, results from the conversation between the child and web teacher regarding person-centred learning and support, accessibility from the parents' point of view, and items and patterns measurable for health and PCC.

4.1. Feasibility and Satisfaction with the Intervention. A web preschool is a new intervention to support children with long-term illness. This study has shown that web-based support in younger children who are not able to read and write is possible. The children found it interesting to communicate with their web teacher on SKYPE, and the story about Sara and Max constituted a good basis for the conversation. The children in the study could find the intervention on the platform and they also received paper copies of the pictures. By using SKYPE, an on-going see-hear conversation was facilitated and the children were able to show the teacher what they liked to illustrate. The teacher for her part was able to watch the child's face and body expressions and respond to them. She could also observe when the child was not focused or too tired to continue. The see-hear pictures were suitable for this type of intervention, giving the child the chance to understand and reflect on the situation. The web teacher was able to vary the theme of the learning process. Similar tools of pictures and photo voice have been used before in information and in support of children face to face [19–22]. The follow-up design allowed the child and teacher to get to know each other, which might have enabled deeper conversation. The phenomenographic method with respect to the development pedagogic method described by Samuelsson and Carlsson was useful for analysis according to the aim [15, 16].

Altogether, 12 children participated in the pilot study, and five of them took part in the follow-up conversation according to the intervention. The number of participants included was not decided beforehand but was dependent on developing suitable intervention. Between 13 and 60 minutes were spent on each conversation on 22 occasions. The web teachers were two of the authors and had special knowledge of preschool children and the method (M. Jenholt Nollbris, PhD, paediatric nurse and A. Simeonsdotter Svensson, PhD, pedagogue).

4.2. Results Person-Centred Learning and Support

4.2.1. Consequences of Playing. This category describes the child's participation in playing in the family and at a preschool setting. Most of the children's narratives were related to playing, and it was important to participate in the playing. The importance of playing in childhood has been stressed many times before [16, 17, 23, 24] and it was therefore not a surprise that the experiences were expressed through playing. Already in 1963, Erikson [25] described from a psychoanalytic perspective that playing can be used as a therapeutic tool for self-care in children, which the present intervention will also support in daily life. Children's hospitals today often use play therapy for learning about a procedure. To follow up the given information and solve misunderstandings, procedural play has been used with good results [26].

In the conversation, the children reflected on situations of which they had experience, and how they thought about these. The child described the pictures he or she had discussed earlier with the web teacher. The teacher affirmed the child by listening to him or her and telling the child that he or she was good at describing. The children did very well with the narration. One reason could be the expectations of the children to respond to the web teacher. Participation by children is stressed as important in the Convention of Children's Right [27]. Children who participated, in planning and decisions at an early age develop an ability to reflect and argue, and this has been shown to facilitate their self-esteem [28]. The latter study has shown that already from the age of two years, children are able to take part in decision-making concerning their health. In the present study, children expressed a need to talk about their experiences; they liked to be addressed and the intervention could contribute to their self-esteem.

(i) Participating in Playing with Family and Friends at Home. In this subcategory, playing in the family and together with friends is described. The child related his or her experience at home by reflecting on what he or she had heard about Max and Sara. The follow-up conversation showed a process of developed understanding, and the child was able to draw conclusions from a certain event to a consequence, a next step in the process, *"The best thing is when there is snow and we can throw snowballs at Daddy. . .Max and Sara go skiing. . . When there's snow outside, you can go on a small sledge, snow racer or throw snowballs."*

The children showed that they participated in the situations that arose and played in the family and together with friends. The children could draw logical conclusions from what was possible in different situations, *"I jumped on the trampoline today; it was very cold; you should have shoes on. My feet were cold."* This quotation has the three steps described by Pramling Samuelsson and Asplund Carlsson: first, the learning objective, second, the general structures became visible to the child, and third, being able to think about one's own learning [16].

Games and playing were regarded as the same thing, but the children knew they could win when playing games. Playing was a common tool to communicate with other children, *"I have been at my friend Johan's house. We usually play games, and the one that is most fun is Mario Kart, a game with two men, one is Luigi and the other one is Mario. You play it on Nintendo. I am very good at it. You can win a cup. It is made of gold and very big."* Playing as a means of communication has been described earlier in a study of preschool children [29].

(ii) Participating in Playing at Preschool. Playing at preschool was something children often talked about. They played together with the other children. This was regarded as the most important thing and proof of participation in the community. The social rules of playing were important; the rules were often set up by the teachers. To be able to participate fully, social and emotional competence is needed, but none of the children who participated in the pilot study had any problem with alienation, *"I was at preschool yesterday, we played outdoors and went down the hill on a bum slider. It didn't go that fast; we had to sit and hold on tight."* This subcategory also had three steps: learning object, general structures, and thoughts about own learning [16]. The following is a quotation by a child describing a game: *"...when you get to 100 you win. I can count to 100. When Max and Sara are at their preschool, they sing the name song. At my preschool we can't sing the name song because there aren't enough children."* The children talked differently about participating in playing at preschool, and the play could be viewed in different ways. They had in common that they described the playing and its consequences in daily life indoors and out. The children also related to Max and Sara and what they did. These findings pointed out the importance of having a common basis for conversation. The story about Max and Sara involved a theme to talk about that did not necessarily need to be too private.

4.2.2. Consequences of Experiences. This category describes the children's experiences and certain emotions concerning them. The pictures in the story about Max and Sara opened up the conversation about feelings. Feelings in general, fear, death, and sorrow, were mentioned by the children but also situations of joy. Their own and others' experiences are central to children in this category. The children described different feelings related to what they had experienced at home and at preschool. The narratives arose from situations in daily life. The experiences could be more or less positive.

According to the intervention, the children were asked by the teacher, "How did it feel in your body?" and "What to do?"

(i) *Feelings Related to Family.* This subcategory shows how children communicate feelings related to the family and between friends. Different feelings and emotions in relation to family and friends can be experienced as caused by someone. Other people and animals are often mentioned by the child. The children in the study were often able to describe experiences in daily life and put words to their feelings. Their feelings were also mostly reflected followed by a solution of what to do when it happened, "I became frightened when Daddy scared me. Daddy and Anton scare me and then you run away."

Some children had experiences of a pet that had died, and they were mostly related to a feeling of grief. But the children did not necessarily relate death to grief, they could just talk about their experiences of a certain animal, "I had a guinea pig and his name was Jeppe. He is dead now. He was grey and white. He was naughty and once he bit my finger." When the web teacher asked how the child had felt when Jeppe died, the child had answered that she felt sorrow. Feelings could be experienced as just emotions raised and not related to any specific event, "I feel like it is jittery and it feels like you are a bit shy."

Other feelings were related to a well-known event and already reflected, such as when the child got hurt accidentally. Then it is regarded as natural to be upset and sad, "I feel sad when I get hurt. Yesterday, I fell with my bike. I got a very big hole in my trousers. It didn't hurt; I wasn't injured." Reflected feelings built on the child's own experience could be put in a new concept that the child could recognize, "Sara is happy, maybe something fun has happened; a friend had been there."

This pilot study indicates that feelings expressed by children may be feelings they know they are allowed to have or can be expected to react to. It means that when a new situation arises when a child is violated/insulted, he or she may not have any words or not even rules to refer to and consequently have a problem telling anyone in a comprehensible way. These feelings could not be reflected in a good way. This stresses the importance of the child's right to integrity and informing and discussing it with the child. Through such discussions in preschool groups, health care professionals and preschool teachers can offer tools to prevent bullying, insults, and sexual abuse.

(ii) *Feelings Related to Preschool.* This subcategory is about feelings related to experiences of the preschool and in the preschool context. Max and Sara's story and the pictures were used as a foundation for the children's own experience to express feelings and reflect on them and also put them into new contexts. They described their reflections as consequences of their experiences, that is, being sad when sad things happened or feeling happy when fun things happened. They showed that they remembered the conversation before and had learned to use words to communicate their feelings. They liked to talk about their experiences of feelings and events when they happened and also to be validated, "One

day Sara didn't want to go to preschool. They had planned to go on an excursion and she was ill. I think she felt sad. I have felt like Sara about not going to preschool; it was boring. It's not fun to go round and round in the forest."

It is not always easy to be a child in a big preschool class. It is different from at home and you have to wait for help. Sometimes, the teachers give attention to other children and a particular child may feel lonely, "Sometimes, I feel lonely." In the preschool setting, the child also tried to relate to his or her experiences of situations that allowed them to feel sad, "Sara is sad, maybe she has got hurt. Once I scraped my knee, then I felt sad." Different rules and acceptance or lack thereof have to be discussed at preschool age by professionals to let the child know what is and is not acceptable and further prevent unnecessary suffering. Sometimes, the children experienced that social rules given by the teachers were not being followed. They expressed feelings of worries and sadness, but because they were rules that everyone knew about, they could complain to the teacher, "You feel sad when someone tells you something not nice/silly. They say...when you are playing and one of them tells you that you are not allowed to join. You feel sad. Then you tell the teacher and the teacher talks to the children who had done the wrong things. Then it starts to be better." In our model of web-based learning and support, we have to be aware of the unspoken information of needs and wishes and ask why children act in different ways. Most children like to be liked other children, but they do not know how to express their needs. This was clearly expressed in an earlier published study of boys on treatment with clean intermittent catheterization. They did not tell anyone that they could not cope with the treatment because they were afraid of being teased. They just stopped the treatment and nobody asked why no catheters were used. [2].

The preschool children also liked to feel pride, and they often talked about their skills being validated, "I can show you a drawing. I am good at drawing." This is a good spur in learning and can be used to overcome difficulties in compensating for important needs in health and when expressing wishes [13, 14, 16].

4.3. *Accessibility of Intervention from the Parents' Point of View.* The parents found that the technical communication, including the children's skills in managing the different buttons, was satisfactory, except in one family that occasionally had a slow connection due to weak broadband. The interviews via SKYPE were experienced as exciting. The parents' participation consisted of switching on the computer and SKYPE and being present in the same room when the child communicated with the web teacher. Parents today are web-based communication and they were able to guide their children if necessary. The parents expressed their appreciation of the aim of the intervention to strengthen what was good and not, as is usually done when visiting hospital, what needed to be better.

4.4. *Items and Patterns Concerning Person-Centring and Health.* The interest in learning and the ability of reflected communication were identified as resources of the preschool

children who participated in the present study. When the child reflects on the story about Max and Sara by talking about their experience, needs can be identified. The children also practise communicating their feelings and wishes. The web teacher has the opportunity to choose certain themes concerning identified needs and wishes and to concentrate on these in the conversation. The intervention design with follow-up conversation facilitates and ensures a person-centred manner according to the method described by Ekman et al. [13].

Signs of well-being, or a lack thereof, are identified in the conversation, as is support from teachers. Feelings of happiness and pride, finding solutions to problems that arise, and further understanding that actions and reactions from other people are not necessarily due to the child are regarded as signs of well-being. This is in harmony with the definition of health described by Antonovsky [14]. However, this study is too small to confirm all the factors (comprehensibility, meaningfulness, and manageability).

5. Conclusions

In this pilot study, we have shown that web-based support is possible for preschool children. Children found it interesting to communicate using SKYPE. The stories about Max and Sara constituted a useful basis for conversations about feelings and participation in playing as an important part of the children's society. The process of learning was supported and shown to be useful: learning something new, reflecting on it, and then using the knowledge in a new context. Items and patterns were identified that were useful for research, considering person-centring, health, and learning. The follow-up interventions after one and two months indicated a development of person-centred learning and support. The individual's resources, needs and intentions were expressed in the present study and communicated in the interaction between the child and the teacher. Support was given as confirmation of the children's narratives and expression of their feelings. Well-being was identified as feelings of happiness, pride, the ability to reach solutions, and understand feelings. Learning about feelings, relationships, and the right to integrity may strengthen self-esteem and well-being and contribute to preventing ill health and isolation at school age. Our findings support the importance of further studying the intervention described in children living with a long-term illness.

Conflict of Interests

The authors ascertain that there is no conflict of interests.

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Research Article

“Keeping the Boogie Man Away”: Medication Self-Management among Women Receiving Anastrozole Therapy

Karen Wickersham,¹ Mary Beth Happ,² and Catherine M. Bender³

¹ School of Nursing, University of Maryland, Baltimore, 655 West Lombard Street, Room 731A, Baltimore, MD 21201, USA

² College of Nursing, The Ohio State University, 378 Newton Hall, 1585 Neil Avenue, Columbus, OH 43210, USA

³ Department of Health and Community Systems, School of Nursing and University of Pittsburgh Cancer Institute, University of Pittsburgh, 415 Victoria Building, Pittsburgh, PA 15261, USA

Correspondence should be addressed to Karen Wickersham, wickersham@son.umaryland.edu

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The oral hormonal agent anastrozole improves clinical outcomes for women with breast cancer, but women have difficulty taking it for the five-year course. The unique medication-taking experiences related to self-management of anastrozole therapy for women with early stage breast cancer are not known. Our purpose was to describe the medication-taking experiences for postmenopausal women with early stage breast cancer who were prescribed a course of anastrozole therapy. Twelve women aged 58 to 67 years, midway through therapy, participated in audio-recorded interviews. Women's medication-taking experiences involved a belief in their importance and an imperative to take anastrozole. We found that women's side effect experiences, particularly menopausal symptoms, were significant, but only one woman stopped anastrozole due to side effects. Medication-taking included routinization interconnected with remembering/forgetting and a storage strategy. Some women noted a mutual medication-taking experience with their spouse, but most felt taking anastrozole was something they had to do alone. Our results provide insight into the way some women with early stage breast cancer manage their hormonal therapy at approximately the midpoint of treatment. Next steps should include examinations of patient-provider communication, potential medication-taking differences between pre- and postmenopausal women, and the effects of medication-taking on clinical outcomes.

1. Introduction

Treatment of cancer has shifted to greater use of oral cancer agents [1], transferring responsibility for medication management to the patient. Therapy with oral aromatase inhibitors (AIs) like anastrozole has been shown to improve clinical outcomes for postmenopausal women with early stage breast cancer [2]; however, women have difficulty taking their medication for the generally prescribed five-year course. Oral AI therapy is a “chronic” care cancer treatment prescribed to prevent recurrence, but most women receiving this treatment do not have active cancer.

Self-management has been defined as one's ability to manage symptoms, treatment, physical and psychosocial consequences, and lifestyle changes that are fundamental to living with a chronic condition such as cancer [3]. Self-management for postmenopausal women with early stage

breast cancer includes medication-taking with oral AI therapy, which requires women to perform activities such as identifying and counting pills, timing of pill taking, and obtaining and refilling prescriptions [4]. Qualitative inquiry provides unique information concerning the medication-taking experiences for patients with chronic disorders [4–6], but little research has focused on the medication-taking experiences for patients with cancer. Ersek et al. [7, 8] explored the reasons patients with cancer have trouble taking their pain medication; however, the purpose of analgesia is different from that of medication for prevention of recurrence of breast cancer. The two published studies examining medication-taking for patients with cancer have been conducted for children or adolescents with leukemia [9, 10], who have different issues related to medication-taking including developmental concerns such as egocentrism, concrete thinking, and parental involvement [10].

Thus, to address this gap in the literature, our purpose was to describe the medication-taking experiences of postmenopausal women with early stage breast cancer who were receiving the oral hormonal agent, anastrozole. We sought to answer the question: “What are the experiences of women who take anastrozole therapy?”

2. Methods

We wished to learn *how* women with early stage breast cancer managed their anastrozole therapy daily [11], rather than whether or not they took it as prescribed [12]. As such, we used qualitative description to generate a complete narrative of the medication-taking experiences of women with early stage breast cancer who are prescribed anastrozole therapy [13]. Qualitative description as a method guides analysis and interpretation of data to produce findings that are close to the data, which is appropriate when little research about a particular phenomenon exists.

2.1. Parent Study. We accessed an existing sample and data from an ongoing study, The Anastrozole Use in Menopausal Women (AIM) Study, which examines the effect of anastrozole on cognitive function in women with early stage breast cancer (“The AIM Study”). The AIM Study includes postmenopausal women less than 75 years old who speak and read English and have completed at least eight years of education. Women are excluded for self-reported hospitalization for psychiatric illness within the last two years, prior diagnosis of other cancers and neurologic illness (e.g., stroke, multiple sclerosis, dementia syndrome), and distant metastases. Women are followed for their five-year course of hormonal therapy. Adherence to anastrozole is assessed continuously using an electronic Medication Event Monitoring System (MEMS) (AARDEX, Ltd.). MEMS is a bottle cap with a microprocessor that records the date and time of each cap opening from a standard medication bottle (i.e., not the weight of the bottle). Access to The AIM Study participants allowed us a unique opportunity to answer our research question about the experience of medication-taking and full scope of medication-taking behaviors in this sample.

2.2. Current Study Procedure. The University of Pittsburgh Institutional Review Board approved the “current study,” a followup to The AIM Study. At the time we began our study (2009), we had complete six-month data for 47 women. The AIM Study PI sent mailings to these 47 women to determine their interest in participating in the follow-up study. We interviewed all 12 women who responded to the mailings. Interested women contacted the researcher (KW), who then described the purpose of the interviews by telephone. All women provided written informed consent prior to their interview.

2.3. Interviews. The researcher (KW) performed in-depth semistructured interviews ($n = 12$), averaging 30 to 40 minutes in length, using an interview guide of open-ended questions adapted from two previous qualitative studies

of medication-taking [6, 14]. Questions included asking women about what it was like to take anastrozole, how and why they began taking it, how it made them feel, how it was different from their previous treatments, how they took it on a typical day and the strategies they used, what they found difficult about taking anastrozole, forgetting to take it, and who helped them manage their medication. Interviews conducted at a convenient private location ($n = 6$) were shorter in duration, but not less informative, than those performed in the participant’s home ($n = 6$). Interviews were audio-recorded with observational notes for recording of the participant’s nonverbal cues and eye contact [13]. Participants received \$10 upon completion of the interview.

2.4. Sociodemographic and Clinical Data. The following demographic and clinical data available from The AIM Study database were used to describe the sample. Sociodemographic information was collected using the University of Pittsburgh, School of Nursing, Center for Research in Chronic Disorders Sociodemographic Questionnaire. Women’s depressive symptoms were measured using the Beck Depression Inventory-II (BDI-II) [15]. Anxiety was assessed with the Profile of Mood States (POMS) Tension-Anxiety subscale [16]. Information concerning stage of breast cancer, tumor type, radiation therapy, and chemotherapy was abstracted from the patient medical record. Side effects of hormonal therapy were assessed with the Breast Cancer Prevention Trial (BCPT) Symptom Checklist [17, 18]. BDI-II, POMS, and BCPT data from The AIM Study 6-month and 18-month time points (closest to the interviews with the most complete data) were used for the analysis.

As another form of description of medication-taking of anastrozole, we categorized women according to their MEMS cap adherence rate: 100% adherers, good-adherers (90–99%), adequate-adherers (80–89%), and low-adherers (below 80%). These categories were based on the literature [14, 19, 20]. We defined adherence as the percent of the prescribed doses taken. Women who discontinued or who were switched to another AI by their oncologist due to toxicities were included, because therapy discontinuation is an important variation (and perhaps consequence) of medication-taking.

2.5. Data Analyses. The researcher (KW) reviewed each transcript while listening to the audiotape with observational notes for accuracy and for an understanding of the participant’s focus. All interviews were transcribed in a word document and then uploaded into ATLAS.ti (6.2.27) (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany) to manage and organize the data. Observational notes were summarized and included with each transcript. We developed a timeline for each woman that outlined the timing of her breast cancer diagnosis, the start of anastrozole, and the side effects she experienced after beginning anastrozole to gain a sense of her overall experience with this treatment. As analysis progressed, interview language was refined for clarity. Probes were added about forgetting

to take medication (e.g., “How did you realize you forgot?”), unexpected events that affected medication-taking (e.g., vacation/travel), and information received at therapy initiation (e.g., “What were you told about Arimidex®?”).

Descriptive statistics were computed using IBM SPSS Statistics v.20.0 (Armonk, NY) to describe the data distributions and to characterize the study sample. We used the independent samples *t*-test (or Mann-Whitney *U*-test, if data were nonnormal) and the Chi-square test of independence (or Fisher exact test, if cell sizes were sparse) to compare women in the current study with women in The AIM Study to investigate whether there were any significant differences between the two groups.

Qualitative content analysis [21] was the primary method for data analysis. For each interview, the researcher (KW) examined the data line by line to label (open code) text related to the women’s medication-taking experiences, using the interview questions as a guide. Similar codes were grouped into categories, which were examined for central themes. Dimensional analysis was applied to themes to detect variations, specificity, and range [22]. Matrices were constructed for comparison and pattern recognition of participant characteristics (sociodemographic, breast cancer type and treatment, adherence level), side effects, depressive symptoms, and anxiety, merging qualitative data, and quantitative measures (BCPT, BDI-II, POMS). Numerical counts were used to characterize the strength of the main themes and subthemes within each case [23]. In this report, we use “most” to describe occurrence of a theme in at least nine women. Turning points in the analysis included the realization that medication-taking occurred despite side effect presence and severity and the pervasiveness of fear of breast cancer recurrence. Sampling, interviewing, and analysis continued until we reached informational redundancy, that is, no new themes or patterns were recognized ($n = 9$); at that time, we enrolled three women for further sample diversity and to confirm existing findings. No new themes emerged and we achieved informational redundancy, but we cannot claim full saturation due to limited access to low-adherers and women who discontinued therapy.

We implemented the following steps to assure the trustworthiness of the data, analysis, and research process. (a) A Co-Investigator (MBH) with expertise in qualitative methods and medication-taking research [6] audited the data by performing dual coding and review of the data to ensure the credibility of the analysis. (b) Four members of a weekly group analysis meeting discussed data exemplars, coding, and analytic decisions. (c) Four follow-up telephone interviews were performed to further clarify developing themes. For example, when several women mentioned that they had friends or relatives who were prescribed anastrozole and were no longer taking it, a follow-up question was added to further explore this experience and key informants (i.e., provided rich data about the selected subthemes) were recontacted to clarify this theme. (d) All interview data, notes, and memos were documented using ATLAS.ti (6.2.27) (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany) software.

3. Results

3.1. Participant Characteristics. Twelve women aged 58 to 67 years were interviewed between June 2009 and April 2010. All women were white and well educated, and were similar to the women who participated in The AIM Study (98.1% white) (Table 1). Eleven women had been taking anastrozole for two and one-half to three years at the time of their interview. One woman discontinued anastrozole after six months due to arthralgias (hip pain) and was then switched to another AI by her oncologist. At the time of her interview, she had discontinued all AI therapy due to side effects. Women in the current study had six-month adherence levels ranging from 38.4% to 100% (mean = 87.8%), which were similar to women participating in The AIM Study (mean = 88.1%).

In their interviews, the women shared their perceptions about anastrozole (“what I think”), their experiences with side effects and side effect severity (“how it makes me feel”), and their day-to-day self-management of anastrozole (“what I do”). These three main topical categories describe the women’s engagement in self-management of anastrozole and represent key dimensions of self-management in this early phase of breast cancer survivorship. These categories involved an overarching belief in the importance of anastrozole, as well as an imperative to take it. We found that though the women’s side effect experiences were significant, only one woman stopped taking anastrozole due to side effects. The women’s descriptions of their day-to-day medication-taking experiences with anastrozole included barriers and facilitators to taking anastrozole daily.

3.2. Perceptions about Anastrozole—“What I Think”: Keeping the Boogie Man Away. All women assigned a sense of the value, purpose, or importance to anastrozole that offset other challenges associated with managing anastrozole, including side effect severity. The importance of anastrozole was defined as a woman’s awareness or beliefs about therapy, the value, benefit, or relative worth of taking anastrozole, and her commitment or motivation to take anastrozole. Most women remained motivated to take anastrozole despite the side effects they experienced:

I still take it. I still take it... if I thought that the medication was going to make me have early-onset dementia, I would think about it more, and I do know there’ve been some thoughts about that, but I still take it. I don’t want to, (lowers tone) get breast cancer again, so, I take it.

When discussing their beliefs and motivation to take anastrozole, most women used imagery rather than the term “cancer recurrence”: “I’m taking it to keep the boogie man away.” Another took it to keep “loose cells [from] travelling where they shouldn’t.” Another woman said, “That’s very important, that pill... I want to live... I want to stay healthy.” One participant with 100% adherence described a heightened consciousness about the role of anastrozole:

I was conscious of saying, “Okay, do your job in there, Arimidex®...” it was a funny thing. I didn’t

TABLE 1: Participant sociodemographic, breast cancer, and breast cancer treatment characteristics.

Characteristic	Current study participants (n = 12)	The AIM Study women who received anastrozole (n = 162)	P value
Age (in years) mean	62.5	60.1	.729
Years of education mean	14.8	15.1	.844
Marital status n (%)			.528
Married	6 (50.0)	109 (67.3)	
Divorced	2 (16.7)	20 (12.3)	
Never married	3 (25.0)	18 (11.1)	
Widowed	1 (8.3)	13 (8.0)	
MEMS 6-month adherence %	87.8	88.7	.129
Breast cancer treatment n (%)			
Radiation therapy	11 (91.7)	32 (19.8)	.874
Mammosite therapy	1 (8.3)	12 (7.4)	
Chemotherapy with anastrozole	2 (16.7)	25 (15.4)	.025*

* $P < .05$.

experience that in the first year and maybe only because I was experiencing those other things [side effects]. But, there was this short period of time where I'd take my water, drink it down and say, "Okay, do your thing, Arimidex®, get in there, kill any cells that you see..."

Conversely to the above description, two women indicated that it was "no big deal" to take or to miss a dose of anastrozole, presumably meaning that missing one dose would not harm her overall outcome.

So I think if you're taking Arimidex® over years, they're [adrenal glands] not going to all of a sudden, if you miss one, they're not going to all of a sudden get back going again when they've been put to sleep as... for as long as they have been... I mean if you skipped a whole month... or even a whole week... that might be a different story... cause then they'd start getting their act back together.

Although all women were motivated to take anastrozole and recognized its value, some interviews suggested tension between the desire to prevent cancer recurrence and uncertainty about taking anastrozole. This woman's comments further revealed ambiguity regarding the value of the medication in preventing cancer recurrence:

To me, the benefit of not getting cancer, whether it's breast or some other site, is certainly more advantageous than putting up with a little bit of wrinkles or some other problem... but on the other hand, you wonder.

Women further indicated that there was a necessity or obligation to take anastrozole that went beyond their belief in its importance. This treatment imperative included her commitment to the program and "wanting to get to the finish line." The imperative was self-motivated, "I would never dream of quitting" "I truthfully want to do the five years.

I want to complete the program as is," or externally motivated from a relative, a friend, or a health care provider, "My mom... would push me to take it and say 'you need to continue on this.'"

Several women mentioned an imperative to take anastrozole based "on doctor's orders." "He told me that I'd have to take it, and so I took it." Women were told by their health care provider (HCP) to take anastrozole daily, but they were they given no other instructions. The women expressed willingness to discuss their side effects with their oncologist or HCP; however, they were rarely asked about their experiences. In some cases, they received conflicting advice from HCPs. For example, when discussing her foot pain, one woman indicated, "Foot doctor says no [unrelated to anastrozole]." Everyone else says "Ah, yeah." Furthermore, when some women desired specific information about anastrozole, such as what time of day to take the medication, they asked their pharmacist (or chemist).

3.3. Side Effects and Side Effect Severity—"How It Makes Me Feel": Being Thrown Back into Menopause. For all women, the opening question ("Tell me about your experience taking anastrozole") led without prompting to a description of the side effects of anastrozole. All women immediately described challenges with hot flashes and associated sleep disturbances, arthralgias, fatigue, "female things", weight gain or loss, and struggles with forgetfulness or memory loss, regardless of their MEMS cap adherence level. The women described the timing of when side effects occurred in relation to starting anastrozole (e.g., within a few months or right away), the time of day the side effects occurred, and the duration of the side effects (e.g., lasting a few minutes). They described how the side effects affected their daily life or altered their lifestyle, characterization (e.g., "like a torch"), frequency (e.g., occurring every few hours), and their attribution that the side effect was due to anastrozole, another therapy, or a process such as aging. One woman experiencing menopausal-like

symptoms stated that anastrozole “threw me back into menopause.” Another woman characterized her hot flashes:

Overall it feels like a torch... the chest area and face and forehead; my forehead's like soaking wet now... they come on real fast and last about a minute or two... during the night I might wake up it seems every two hours... like at midnight, two o'clock, four o'clock, six o'clock, and you know it wakes me up and sometimes I can't go back to sleep so that is an additional problem.

One woman who took anastrozole in combination with chemotherapy described how she felt about her experiences with memory problems:

The only thing I do have a problem with, and I have noticed it, is my memory. Now I'm remembering a lot of things... today, talking to you, but if somebody said, "Well, I told you that yesterday," or "Don't you remember I..." "I can't remember." I have to really think, and that scares me. I mean I had a bad memory before (laughs)... but it, it is worse. It is, it is worse.

The woman who discontinued AI therapy due to hip pain described the related uncertainty of the underlying cause of her pain:

I think once you have cancer you start to think, "Is this mets to the bone, or is this mets somewhere else... or is it a side effect from the medication"... when I take medication, I try not to read the side effects unless I'm having problems and then I go to the side effects and say, "Ah, yeah, maybe this is it." But when I started... in my hips, and it was at night and I was having trouble sleeping, I just decided that... this [anastrozole] wasn't for me.

To further explore the problem of the women's side effects and side effect severity, we constructed profiles of side effects for each participant by combining those side effects reported in interviews with information from the BDI-II, POMS, and BCPT (Table 2). Participants reported three to six side effects; most women ($n = 10$) reported five or more side effects. The two women classified as “low-adherers” reported the same type and number of side effects as the two 100% adherers. The woman who discontinued AI therapy due to side effect severity was classified as a “good” adherer and reported the same five side effects as the other women. Women expressed varying levels of depressive symptoms and anxiety when completing the BDI-II and POMS surveys; however, only one woman expressed these symptoms during her interview, and her scores did not indicate depression or anxiety. This mixed data analysis revealed no patterns between symptom number, type, and severity and adherence category.

Generally, women used pharmaceuticals (e.g., antidepressants), physical therapy, or other daily management or compensation strategies to alleviate the side effects they

experienced. For example, one woman avoided or limited her activities, while another wrote down tasks or names to remember them. The woman with “summertime blues” described her frustration with word-finding problems and how she compensated:

I've worked with lots of women, and we all say (laughter) estrogen, the menopausal breakdown. But, I have days when I just... can't remember things like names or specific words for thoughts... And I'm usually really good. I love words, and I'm usually pretty good with them. But, I just have days when I can't, and I'm not as articulate... I just finished helping with the summer camp and we had about 18 college counselors... I remembered all their names, and once in a while I'd completely blank... but I had a notebook, I had my cheat sheet.

3.4. Day-to-Day Self-Management—“What I Do”: Doing It Yourself

3.4.1. *Barriers.* All women described in detail the actual hand-to-hand, tangible characteristics of taking anastrozole. Many women mentioned that the pill was tiny and easy to swallow. However, when anastrozole was packaged in blister packs for a short time (e.g., a few months), the women expressed extreme difficulty and irritation with opening the blister pack. One woman who received two three-month supplies of anastrozole packaged in blister packs described how the packaging affected her daily medication-taking of anastrozole:

... My husband had to get them out... Arimidex® people ought to know that that is not acceptable. (Laughter) Maybe they found that out... but I'll tell you that was the only time that I considered stopping. Because I have arthritis in my hands... and they're old hands... it was very, very difficult. I couldn't put it through, you know, so I tried to use a penknife, I tried to flip up the little foil thing... and sometimes I'd try to slice off the bubbles like this. (Gestures). It's just hard. I couldn't do it.

3.4.2. *Facilitators.* Central to self-management of anastrozole for all of the women was the routinization or integration of anastrozole into their everyday lives as anastrozole-taking became a consistent, accepted, or habitual medication self-management practice. They described timing anastrozole administration with meals or other medications, associating it with a visual cue (e.g., seeing the bottle on the window sill), a central location (e.g., kitchen), or a storage strategy (e.g., weekly pill minder). Women stated that participation in The AIM Study helped to routinize their medication-taking practice. Most ($n = 11$) were already taking other prescription medications, vitamins, or supplements and incorporated anastrozole within their established routine.

TABLE 2: The women's self-reported side effects.

ID	Hot flashes	Arthralgias	Sleep disturbance	Fatigue	Weight gain or loss	Anxiety/depressive symptoms	"Female things"	Cognitive problems
1	B	Both		I	B	BDI-II, P		B
2		Both	I		B	BDI-II, P	Both	Both
3*		Both			B	BDI-II, P, I	BCPT	I
4	Both		I		B	BDI-II, P	Both	B
5	B				Both	BDI-II, P		B
6	Both	B	I			BDI-II, P	B	B
7	Both	B			B	BDI-II, P	B	B
8	Both	B	I	I	Both	BDI-II, P		Both
9	Both	B	I	I	B	BDI-II, P		B
10	Both	Both	I			BDI-II, P	B	B
11	B	Both			B	BDI-II, P	B	B
12	Both	Both	I	I		BDI-II, P		Both

Arthralgias were defined as aches, pains, and joint pains. "Female things" were defined as vaginal itching, vaginal bleeding, vaginal discharge, or pain with intercourse.

B: Symptoms reported by the participant on the Breast Cancer Prevention Trial (BCPT) Symptom Checklist only.

I: Symptoms reported by the participant during the interview only.

Both: Symptoms reported by the participant in both the interview and the BCPT.

P: Anxiety reported by the participant in the Profile of Mood States (POMS) Tension-Anxiety Subscale.

BDI-II: Depressive symptoms reported by the participant in the Beck Depression Inventory-II Scale.

*This participant was the only woman to specifically express depressive symptoms or anxiety in her interview.

Associated with routinization was remembering/forgetting to take anastrozole and their realization, reaction, and strategies for taking anastrozole after forgetting a dose:

I was in that AIM Study and I had the little bottle, and I swear I took it every day, but there was a few times when she (study nurse) put it on the little machine to see that I had missed it a few times. Now last night I went to bed and I remembered about 1:00 [AM] and I came down the steps and took it.

Frequently, remembering was linked to a certain time of day or a storage strategy, such as a weekly pill container. For example, one woman stated she did not forget to take her anastrozole "Cause I take it with my morning vitamin, my calcium, and fish oil." Another woman described:

When I started it, that's when I put into my day [pill minder]... I've had no trouble remembering to take it, and that seems to be a good time [after supper] since its after my work day, except when I have a meeting, I don't forget.

Although women felt they remembered to take anastrozole, over half stated they occasionally missed a dose, only realizing it when noticing the pill was still in the container or her pocket, or when the MEMS cap was downloaded. Both low adhering women discussed the management of their missed doses in a similar manner.

Sometimes I might play the 12 hour shuffle if I know I didn't take it the night before... maybe I'll take it in the morning, and then at bedtime, so

it's probably putting two in one day, but trying to spread them apart, so it's not quite the same.

Some women described medication-taking as a social or a "mutual medication-taking" experience, referring to taking anastrozole at the same time a spouse or other family member took their own medications. Several women mentioned that they had friends or relatives who were prescribed anastrozole and were no longer taking it, but they denied that this deterred them from taking their own anastrozole. Most women described a "solitary" experience in which no one can or needs to help with taking anastrozole. A woman who lived alone stated, "I just have to do it." Another stated, "... I don't think he [husband] thinks about me taking my medication at all."

4. Discussion

Our purpose was to describe the medication-taking experiences of postmenopausal women with early stage breast cancer who were receiving anastrozole therapy. The women's engagement in the self-management of anastrozole involved a predominant belief in the importance of anastrozole, as well as an imperative to take it. We found that though their side effect experiences were significant, the women remained motivated to take anastrozole; only one woman stopped taking anastrozole due to side effects. All medication-taking practices were facilitated by routinization that was interconnected with remember/forgetting to take anastrozole and a storage strategy (e.g., pill minder). Some women noted a mutual medication-taking experience with their spouse, but most felt that taking anastrozole was something they had to manage alone.

Little research has addressed motivation to take oral AI therapy for women with breast cancer. For example, The ATAC Trialists' Group [2] found that fewer women withdrew from therapy with anastrozole when compared to tamoxifen, but the reasons for discontinuation were not reported. In a qualitative comparison of 13 stroke patients who were classified as high- and low-adherers, Chambers and colleagues [24] found that both groups reported intentional and nonintentional adherence. Although some low-adherers in Chambers' [24] study reported occasionally skipping a medication, stability of a medication routine and beliefs about medication were central themes describing medication self-management in our sample. Pound and colleagues [25] discussed in a metasynthesis of qualitative studies of lay medication-taking experiences that little research focuses on men and women who reject their medications or take their medications without questioning. Our results suggest that some women who take anastrozole without question may do so because they believe in the medication's value and importance. Furthermore, the use of imagery and personification in many of the women's speech is additional evidence of the value and power that the women assigned to anastrozole.

The side effects the women reported were consistent with reports of menopausal symptoms induced by breast cancer treatment [26, 27], as well as with previous qualitative research describing women's experiences with hot flashes, the impact of hot flashes on daily life, and the higher priority that women placed on breast cancer treatment over menopausal symptoms [28–30]. Garreau and colleagues [31] found that women receiving AIs switched therapy more often (47.5%) than those taking tamoxifen (37%). Sedjo and Devine [32] found that 30% of women discontinued AI therapy; of those, 84% discontinued due to side effects.

Given these findings, we would have expected women in the current study to describe switching or discontinuing AI therapy more often, but 11 of 12 women indicated that side effects did not deter them from taking anastrozole. The fact that the women who were lower-adherers reported the same type and number of side effects as women who were 100% adherers is interesting and suggests that side effects related to AI therapy are significant to women midway through treatment. The impact of side effects on the medication-taking process with AI therapy for breast cancer prevention requires further examination. It is possible that completion of the BCPT, POMS, and BDI II surveys may have primed the women to describe the side effects that they felt were the most important, most persistent, and/or most present.

The manner in which women logistically and socially managed anastrozole therapy was consistent with research examining medication-taking for patients with chronic conditions [4, 6, 32, 33]; however, in our study, mutual-medication taking went beyond social support or reminding or assisting patients with their medications [4]. Rather, it included a partnership with a spouse in the physical taking of anastrozole that was part of her daily routine. Furthermore, self-management of medications often involves coordination between the patient and the health care team, but in the current study, the women received little in the way

of instructions concerning medication use, side effects, and daily management of anastrozole. This suggests that patient-provider communication and information provision are potentially unmet important needs for women taking anastrozole therapy.

The most significant limitation in the current study is the potential influence of participation in The AIM Study. The women who participated in the interviews were neither naïve to research nor to anastrozole adherence, which may have affected their responses. We interviewed all women who responded to the mailings, but most of the women were already successful in self-management of anastrozole. Women may have had difficulty recalling their early experiences taking anastrozole, or they may have been primed to discuss side effects due to the recent completion of The AIM Study surveys.

All women in the current study were white and well educated. Although the women we interviewed were representative of the women who took anastrozole in The AIM Study, they may not represent postmenopausal women with early stage breast cancer in the general population. Racial/ethnic disparities in treatment may affect self-management of medication and should be investigated.

Qualitative description allows one to fully describe a particular phenomenon; however, our sampling strategy did not allow us to obtain a complete picture of the women's process of taking anastrozole. In the current study, the women were approximately midway through their five-year course of therapy; therefore, they may have been more established in their medication-taking routines and less likely to discontinue anastrozole therapy. Interviewing women at earlier points in their treatment may help elicit the full scope of how side effects of hormonal therapies affect medication-taking.

The women in the current study were mostly 100%- or good-adherers. While we reached information redundancy in our sample, we did not saturate with regard to those who were low-adherers or who had stopped AI therapy. We were able to interview one participant who had discontinued anastrozole due to hip pain; however, we may have missed women at the beginning of their treatment who discontinued or were switched to other AIs. Nonetheless, our results provide a snapshot of the way some women at approximately the midpoint of their hormonal therapy manage their medications, and thus may inform interventions that would aid them in completing the full five years of anastrozole therapy.

5. Conclusion

The women's experiences suggest several implications for clinical practice concerning medication self-management. Given that women were offered minimal information about taking anastrozole therapy, provision of information about anastrozole, its side effects, and how and when to take it may be beneficial, beginning with the first clinic visit with ongoing reassessment at subsequent clinic visits. Second, while most women indicated they experienced similar side

effects, the trajectory of those side effects differed among the women. This suggests that ongoing side effect assessment by the health care team is needed even after therapy is well established. Finally, questions focusing on the patient's medication-taking experiences as a whole, rather than an overall verbal assessment of adherence, may prompt further discussion, including why they do or do not take their medication.

Our study offers a unique perspective into the medication-taking experiences of some postmenopausal women with early stage breast cancer who were midway through a course of anastrozole who were successful at self-management of anastrozole therapy. While reports examining the end result of self-management of medication (adherence) have been published, reports of research explaining how women view their experiences taking oral hormonal therapy are lacking. Our results help explain why some women, regardless of their measured adherence level, take anastrozole therapy without question and continue despite the side effects of anastrozole. Next steps should include investigations of medication-taking about: (a) women who are low-adherers to AI therapy; (b) socioeconomically and ethnically diverse patient samples; (c) potential differences between pre- and postmenopausal women, particularly side effect severity and medication-taking; (d) effects of medication-taking on clinical outcomes; and, (e) women with breast cancer taking oral targeted therapies.

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Research Article

Coping Experiences: A Pathway towards Different Coping Orientations Four and Twelve Months after Myocardial Infarction—A Grounded Theory Approach

Mari Salminen-Tuomaala,^{1,2} Päivi Åstedt-Kurki,¹ Matti Rekiaro,³
and Eija Paavilainen⁴

¹Department of Nursing Science, University of Tampere, Pirkanmaa Hospital District, Science Center, Finland

²Mari Salminen-Tuomaala, School of Health Care and Social Work, Seinäjoki University of Applied Sciences, Koskenalantie 17, 60220 Seinäjoki, Finland

³Matti Rekiaro, Centre For Pharmacotherapy Development, The Hospital District of Southern Ostrobothnia, Central Hospital, Hammeksenrinne 7, 60220 Seinäjoki, Finland

⁴Department of Nursing Science, University of Tampere, Etelä-Pohjanmaa Hospital District, Finland

Correspondence should be addressed to Mari Salminen-Tuomaala, mari.salminen-tuomaala@seamk.fi

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Background. Patients recovering from a myocardial infarction (MI) are faced with a number of serious challenges. *Aim.* To create a substantive theory on myocardial infarction patients' coping as a continuum. *Methods.* Grounded theory method was used. Data were collected by using individual interviews. The informants were 28 MI patients. *Results.* The core category "coping experiences—a pathway towards different coping orientations" includes 2 main categories: "positive and negative coping experiences" (4 months after MI) and "different coping orientations" (12 months after MI). *Conclusion.* Coping with a myocardial infarction is a long-term dynamic process of dealing with varied emotions and adjustment needs. Coping is threatened, if the patient denies the seriousness of the situation, suffers from depression and emotional exhaustion, or if there are serious problems in the interaction with family members. This study stresses the importance of recognizing the patient's depressive state of mind and the psychological aspects which affect family dynamics. A more family-centered approach involving a posthospital counseling intervention is recommended. *Relevance to Clinical Practice.* The results of this study can be used in nursing care practice when organizing support interventions for myocardial infarction patients.

1. Introduction

This paper presents the findings of a study that explored patients' coping experiences during the first year following a myocardial infarction (MI). Earlier studies have shown that successful coping is difficult even a year after an MI [1–6]. Effective coping following an MI calls for knowledge of the disease and of the desired effects of treatment and medication, as well as resources, a problem-solving attitude, and a sense of personal motivation [7–17]. In order to participate in all phases of MI care, patients need to be made aware of their right to participate [18].

Patients recovering from a myocardial infarction are faced with a number of serious challenges. Plenty of research has shown that besides physical suffering, patients commonly experience severe stressors and other psychological difficulties. These involve feelings of vulnerability [11, 18–21], fear of death, posttraumatic stress disorder [22–26], loss of control [22–26], anxiety [2, 3, 6, 20, 23, 27–30], and depression [31–36]. Particularly the importance of identifying incapacitating depression and anxiety has been emphasized in research [27–34, 37–41]. Depression may manifest itself as loss of energy, irritability, and reduced capacity to solve problems, and it may seriously impact

on family functioning [27–34, 37–41]. Patients may also lose confidence in their bodily capabilities and functioning in work and family relationships [42, 43]. The negative effects of emotional distress on the recovery following MI make it important to study patients' coping experiences and strategies [42, 43].

Post-MI survivors attempt to make sense of what has happened in order to regain a sense of control [40]. They also have to change the patterns of their lives and action [12, 37]. It is not easy to integrate treatment-related behaviour patterns into one's everyday life or to give up old habits. The need for change is often both behavioural and psychosocial. As patients comprehend the extent of the life style changes required, they may experience further feelings of powerlessness and anxiety [40–42].

The influence the MI has on patients depends on their perception of the situation and on their coping ability [1, 40–42, 44]. Coping is defined as the constantly changing cognitive and behavioural efforts used to manage specific external or internal demands that are appraised as taxing and that may exceed the resources of the patient [45]. It includes context-specific, behavioural, and emotional processes in which the patient appraises, encounters, and recovers from contact with a stressor. It is also possible to distinguish between two types of coping strategies. Patients may use problem-focused coping strategies, in which they try to change the situation, or emotion-focused coping strategies, in which they try to regulate the emotions caused by the situation [45].

The coping process may include different stages. For example, Fleury et al. (1995), who studied women's experiences from 8 weeks up to 3 years after the MI, found the process to consist of three stages: surviving, originating, and patterning balance [46]. These stages illustrated the women's movement toward a new perspective on life and personal growth [46]. In the first stage they experienced feelings of inner chaos, isolation, and need to examine values and beliefs. It involved emotional and physical challenges that incorporated the search of personal meaning and an examination of valued relationships. Within the process of originating they created new patterns for living their lives, new expectations of self, and new ways of viewing the world. In the stage of patterning balance, their growth continued through challenges and sustained uncertainty related to MI [46]. According to Kristofferzon et al. (2008) most of the patients moved on and began to regain a balance in everyday life, but some patients experienced large difficulties with managing their everyday life and felt a lack of support from their social network [44].

Sense of coherence is another important concept in the context of coping. A sense of coherence means that one's life has worth, meaning, and purpose. It can be seen as consisting of comprehensibility, manageability, and meaningfulness [47]. Comprehensibility means that patients can make sense out of situation. Manageability means that they have resources to meet various demands. Meaningfulness refers to an individual's belief that these demands are worthy of engagement [47]. Patients' initial perceptions of illness are important determinants of different aspects of recovery after

myocardial infarction. Similarly, patients' view of the future has a great impact on the strategies which they select during the coping process [7, 8, 37, 47–51].

Currently, there are not enough longitudinal studies on post-MI patients' coping and on factors affecting their coping throughout the recovery process [2, 3, 6, 13]. In this study, the aim was to create a substantive theory on MI patients' coping. For that purpose, the patients' experiences 4 and 12 months after an MI are described. Another aim was to understand the social and interaction processes during the convalescence period after the patients' discharge from hospital.

The results of the study can help nursing and medical professionals understand in what kind of issues and situations their patients most need their support. It is also important to make visible the patients who need the most support and counselling in order to achieve control over their disease. This might help to choose the appropriate interventions to promote the patients' adherence to health behaviour change [9–12, 14, 17] and to reduce psychological distress in order to improve long-term prognosis and quality of life [7, 8, 15–17].

2. Methods

A grounded theory methodology was selected because of its focus on the informants' personal experiences and on the identification of interaction influences. The methodology is also suitable, because a new perspective on everyday phenomena was required, both conceptually and from the viewpoint of describing the interactive process [52].

2.1. Sample and Data Collection. Theoretical sampling was selected in order to identify the patients' coping experiences. All the participants selected had personal experience of MI and of seeking to cope with it; they were seen as experts of their own situation. The purpose of theoretical sampling was to collect data that would maximize opportunities to develop concepts in terms of their properties and dimensions, to uncover variations, and, finally, to identify relationships between concepts. The data were collected until saturation was reached. The researcher continued selecting interviewees until they were saying nothing new about the concepts being explored [52].

The data were collected in 2006 and 2007 by using individual interviews. The informants were 28 patients, who had suffered a myocardial infarction (Table 1). The age of the patients varied from 32 to 82 years. The inclusion criteria were a first-time myocardial infarction and no cognitive or memory problems. Most patients, 25 out of 28, had had ST segment elevation myocardial infarction (STEMI), whereas 3 patients had suffered non-ST segment elevation myocardial infarction (NSTEMI). The majority of the patients, or 16, had been treated by percutaneous coronary intervention (PCI), 6 had had coronary artery bypass grafting (CABG), and 6 patients had received medication treatment for their condition. The informants had not been involved in any major rehabilitation programmes, although a few patients

TABLE 1: Characteristics of the study participants.

Characteristics of the participants	
Characteristic	Number
Gender	
Male	16
Female	12
Age	
Mean	65
Range	32–82
Type of MI	
STEMI	25
NSTEMI	3
Treatment procedures	
PCI	16
CABG	6
Medication	6

had participated in 2-day rehabilitation courses. Half of the patients had suffered from angina pectoris after MI, and three persons reported persistent symptoms of heart failure at 12 months following MI, whereas there had been no cases of atrial fibrillation after discharge from hospital. None of the informants had previous diagnosis of depression and none of them used psychoactive drugs.

Potential informants in one university hospital and one central hospital, from a single ward in both hospitals, were approached by cardiac nurses in a counselling situation. These nurses were either ward managers or registered nurses appointed as rehabilitation counsellors, and they were not directly involved in day-to-day patient care. Patients with no apparent cognitive deficits were given introductory letters summarizing the purpose of the study, with the assurance, both orally and in writing, that their narratives would be treated confidentially and that they could withdraw at any point. Written consent was obtained from all the participants when they were still hospitalized for acute MI. In order to ensure a good quality of selection of the participants the researcher had counselled the cardiac nurses about the content of information to give to the patients before starting the selection of the participants. In addition to oral instructions to the cardiac nurses the researcher also provided them with a written information sheet which included the purpose of the study, inclusion criteria to choose participants (a first-time myocardial infarction, no diagnosis of dementia, and no cognitive or memory problems), and ethical viewpoints to help nurses to select the participants.

The interviews were conducted by the same researcher in the patients' homes 4 and 12 months after the myocardial infarction. It was thought that by 4 months, having had their medical follow-up visit at 2 months following MI, patients would have become fully aware of their changed situation and its consequences. The interviews lasted 60–90 minutes, with the mean length of 75 minutes. The interview questions, based on the study aim, were flexible, so as not to constrain the theory development [52]. Each interview was opened with the question, "Please tell me about your coping with

myocardial infarction," and the interviewees were asked to freely describe their experiences. Each individual interview brought depth and helped to further develop the subsequent interview themes [52]. The researcher audio-taped and transcribed the data on computer by permission of the participants. The data amounted to 640 double-spaced pages altogether, with the mean length of transcript being 12 pages.

2.2. Data Analysis. The two sets of data, gathered 4 months and 12 months after the patients' MI, were analyzed separately using the grounded theory techniques [52]. The transcripts were examined line by line for emerging themes, and these themes were used to inform further data collection and analysis. The data were analyzed by using constant comparison. The questions and comparisons evolved during the data analysis guided the theoretical sampling, which was continued until saturation was reached. The analysis was based on Corbin and Strauss's inductive methodology of three coding phases [52].

Open coding began by listening to tape-recorded interviews and by reading transcripts to ensure the accuracy of the text. At the first level of coding, the data were analyzed line by line picking out all the original expressions concerning the patients' experiences of coping with acute myocardial infarction. This coding was guided by questions "What is happening and being expressed here, what does it mean, what is essential and in what context are the interaction and other action taking place?" The coding process led to segmentation of the data into smaller codes, which were labeled according to their meaning. Data were compared with data to find similarities and differences. The open codes helped to separate data and to see relevant processes, and the coding helped to focus further data collection [52].

Similarities were identified in original expressions, which were combined into empirical codes. These were formed into substantive codes, which were divided into subcategories according to code properties [52]. 11 subcategories were formed. At the stage of axial coding, the properties and dimensions of the contents of each subcategory were examined. The subcategories with similar properties and dimensions of contents were combined into 2 main categories describing concepts of the patients' coping experiences.

The analysis proceeded through to the selective stage of producing a core category, which combined all concepts created up to that point. This category was labeled "coping experiences—towards different coping orientations." The concepts describing the elements in the patients' coping between the early recovery phase (4 months) and later recovering phase (12 months) give new information about the phases of the coping process (Figure 1).

2.3. Ethical Issues. The study conforms with the principles outlined in the Declaration of Helsinki [53]. Participation in the study was voluntary and based on the informants' informed consent. Confidentiality and possibility to withdraw at any time were emphasized and special attention paid to the protection of the patients' psychological and physical

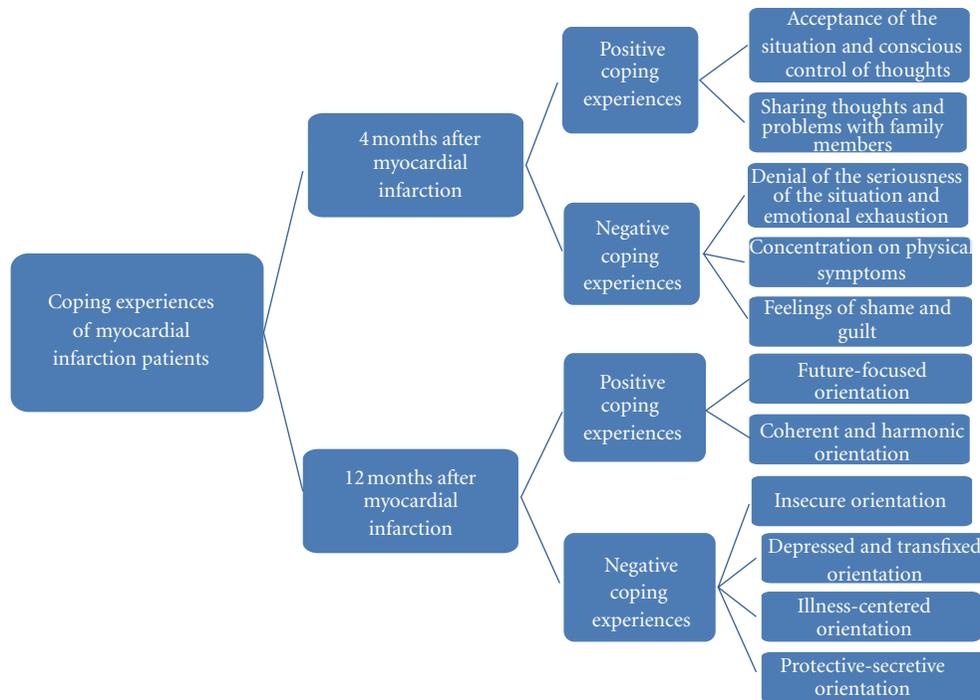


FIGURE 1: Different coping pathways towards different coping orientations.

condition. This report does not include any private data that identify the participants.

3. Results

The core category “coping experiences—a pathway towards different coping orientations” describes the participants’ experiences of coping with myocardial infarction as a continuum. The social and interaction processes during the convalescence period emerged from the data that explain participants’ coping as different pathways. There are causal conditions and contextual and intervening conditions related to the coping experiences 4 months after MI and different coping orientations 12 months after MI. The causal conditions include MI as a disease, its prognosis, and treatment. The contextual conditions include events and participants’ emotional, social, and physical environments 4 and 12 months after MI. The intervening conditions are general conditions that have a bearing on different action and interactional strategies. The intervening conditions may be due to the patient-dependent or the family-dependent characteristics. Family dynamics has an essential meaning for emerging of different coping orientations.

The following description of the patients’ coping experiences 4 months and 12 months after the cardiac infarction presents two main categories. The main category “positive and negative coping experiences” describes the patients’ experiences 4 months after the cardiac infarction and the main category “different coping orientations” their experiences 12 months after cardiac infarction.

Positive coping means that the person has accepted the situation and is ready to continue life, whereas negative coping refers to psychological immobilisation, not being able to move on or to accept and deal with the seriousness of the situation, often combined with continued focus on physical symptoms. The main category “positive and negative coping experiences” 4 months after MI was found to include two positive subcategories: firstly, acceptance of the situation and conscious control of thoughts and secondly, sharing thoughts and problems with family members. It also included three negative subcategories: denial of the seriousness of the situation and emotional exhaustion, concentration on physical symptoms, and feelings of shame and guilt.

In the main category, “different coping orientations,” the analysis of the second set of data (12 months after MI) resulted in the positive subcategories future-focused orientation and coherent and harmonic orientation. It also included four negative subcategories: insecure orientation; depressed, transfixed orientation; illness-centered orientation; protective-secretive orientation.

3.1. Positive and Negative Coping Experiences 4 Months after the Myocardial Infarction. The patient interviews revealed that the seriousness of a lived-through myocardial infarction often does not take shape until 3 or 4 months after the acute situation. The participants in this study reported that the short hospital stay did not allow assimilation of all the information concerning life changes and follow-up treatment at home, and they hardly had the energy to concentrate on future. The participants described their confusion and tiredness at home after discharge. Only after

some weeks did they begin to awake to reality. A 58-year-old working male described his situation as follows:

In the hospital I tried so hard to cope with the situation that I did not realize the seriousness of the situation. When I came home I awoke to reality and realized how close I had come to dying.

3.2. Positive Coping Experiences

3.2.1. Acceptance of the Situation and Conscious Control of Thoughts. Some participants described their acute myocardial infarction as a situation, which simply had to be encountered and accepted. They considered the infarction either their destiny or a part of normal life, something that could happen to anyone and had to be lived through. Some participants spoke of the MI as having a positive impact on their life, because it had made them reflect on their values and on the meaning of life from a new perspective. In some families, the disease had brought the family members closer to one another. The majority of the participants in this study regarded it as essential to accept the situation sooner or later.

It seems that the majority of the participants interviewed for this study were not willing to give up. Many of them described the illness as a life situation, which could cause depression and hopelessness, unless they deliberately maintained a positive attitude to life. By an optimistic attitude they meant serenity, trust, and perseverance. These participants felt that they were able to affect their life course. They referred to their zest for life and happy mood and remained positive and hopeful. The time directly after the MI was understood as a resting time, suitable for renewing physical and emotional resources and for preparing for a future of good and happy things. These participants experienced that they had the possibilities and resources required to achieve their various goals. They also developed dreams regarding their future.

Many participants' serenity seems to be based on a long life experience of coping with trials and troubles. Having earlier undergone difficult situations or diseases, they were able to rely on repeating their positive coping experiences. These interviewees evidently retained their mental balance and courage for life during convalescence without major emotional turmoil, continuing their normal life throughout the sick leave.

The majority of the participants in this subcategory, especially men, considered it very important to control and manage their thoughts consciously. They tried to forget their pains and other symptoms by concentrating on pleasant and comfortable ideas. There was deliberate avoidance of thinking of MI in terms of illness. These persons did not deny the seriousness of the situation, but they made a conscious choice to concentrate their thoughts on more positive aspects of life.

Besides seeking to control their emotions by means of positive thoughts, the participants concentrated on solving problems in a logical way. They felt that they managed their

own life and should not try to accommodate themselves to anybody's overprotectiveness.

3.2.2. Sharing Thoughts and Problems with Family Members. All patients in this study received some degree of social support from their families; 3 persons mentioned friends as their most significant source of support. The support from the family facilitated the participants' coping by enhancing their trust in their ability to deal with the illness and recovery time at home. Compassion and understanding were forthcoming; the participants reported that they were able to share their burdens.

3.3. Negative Coping Experiences

3.3.1. Denial of the Seriousness of the Situation and Emotional Exhaustion. Some participants interviewed for this study were inclined to deny the seriousness of the situation. They tried to avoid thinking about the disease and its symptoms, concentrating on current news and events instead. More men used gallous humor in order to relieve their stress. Denial can also be seen as an essential way to cope with a difficult situation. It gives time and room to gather one's psychological resources to adjust to the situation.

Four months after the MI, many of the participants still felt physically and emotionally drained. They explained how their everyday lives were characterized by lack of resources. Some of the participants interviewed tried hard not to think about the MI, ignoring physical symptoms and shunning emotions related to their situation. Some of them reported severe tiredness and exhaustion four months after the MI, having struggled to endure and control insecurity in order to protect their family members.

The emotional exhaustion of these participants manifested itself in depressive and hopeless thoughts, circling around themselves. They did not trust their ability to return to normal life, thinking that they would have to give up work or planning for future. Some of them felt that they had failed in their life. In patients representing this subcategory, the exhaustion was not accompanied by severe physical symptoms.

3.3.2. Concentration on Physical Symptoms. Many participants in this study experienced that they had not recovered well from the MI, because they still suffered from angina pectoris, arrhythmia, and dyspnea. The presence of these symptoms induced fear of recurrence of the infarction. The life of these men and women concentrated on their physical symptoms. They explained that the symptoms controlled their everyday life; they were conscious of their physical condition all the time. This was experienced as very stressful.

3.3.3. Feelings of Shame and Guilt. Many of the working-aged men and women interviewed for this study found it shameful to stay at home during their convalescence. They would have preferred to work and participate in normal social life. Being idle was particularly difficult for men, who considered themselves as the family breadwinners. They felt that they

had let down their spouses and experienced guilt, seeing their spouses attending to all the housework after full days at work. There were also concerns that the neighbors might regard the convalescents as lazy work evaders. A few participants expressed their feeling that the MI might diminish their value as citizens, as they would not be able to contribute during their sick leave.

Most of the men were also irritated at what they considered their spouses' overprotectiveness. They felt that the wives kept an eye on them all the time and that they were not trusted anymore. Women reported that they would have liked to contribute more to housework, but their spouses would not allow them to do that. Both men and women experienced that they had lost a part of their independence and personal space, being under the spouse's controlling eye.

Some men experienced shame, because their employers did not understand the seriousness of the illness, but demanded their return to work as soon as possible. This was a situation with conflicting interests to the men, who were willing but unable to resume work.

3.4. Different Coping Orientations 12 Months after the Myocardial Infarction. In the analysis of the second set of data, which describes experiences 12 months after the MI, the participants' positive coping experiences were found to involve a future-focused orientation and a coherent and harmonic orientation. Finally, there were four subcategories of negative coping experiences: an insecure orientation; a depressed, transfixed orientation; an illness-centered orientation; a protective-secretive orientation.

3.4.1. Future-Focused Orientation. Most of those men and women, who expressed a positive attitude to future, were still in working life. Their thoughts seemed to be very much focused on future. Half of all the interviewees believed, for example, that it was important that they took responsibility for their own treatment, medication, and lifestyle changes. Many of them had acquired knowledge about the disease, making an effort to prevent complications and recurrence. As far as their future and health were considered, they considered themselves the responsible key persons. These participants also recognized and discovered new challenges and possibilities. They explained that, having by that point dealt with some difficult emotions and fears regarding MI, they now were able to trust their coping abilities. It was typical of these participants that they had been able to accept the situation and discuss it with their families already 4 months after the infarction.

3.4.2. Coherent and Harmonic Orientation. Most of those participants, whose attitude to life was one of serenity and harmony, were elderly. One third of all the participants said that their life was balanced 12 months after the MI. They declared that their life had a meaning, it was harmonic, and they had reached an equilibrium of emotions. These men and women had confidence in life tomorrow, belief in God, or trust in their own capabilities to control their lives. For them, coping meant mastering one's feelings when possible and

accepting the inevitable when not. Some of them had been compelled to cope with significant loss earlier in their lives, and they had managed to do so without getting depressed.

All the participants with this orientation had accepted their situation already 4 months after the infarction, and their life at 12 months after the MI made an impression of a serene, harmonic continuum. The participants in this group had also felt supported by their family members.

Many participants in this study emphasized how important it was to be able to return to everyday life and enjoy routines and habits. This was a way to reduce stress and worrying. Their experiences revealed the importance of concentrating on positive and empowering things, instead of occupying oneself with illness, symptoms, and limitations. They also said that coping meant breaking problems into manageable bits and working them through one at a time.

3.4.3. Insecure Orientation. Some of the participants interviewed for this study experienced that they did not have adequate information about their followup and self-care even 12 months after the myocardial infarction. They declared that they would have needed clearer guidelines concerning the rehabilitation process. The follow-up appointments with medical or nursing staff had stopped at 2 months after the MI, and the participants felt left to fend for themselves.

These participants were anxious because they were not certain how much they were allowed to stress their body; they lacked the proper insight on the limits of their physical condition. They explained that they did not know when and how to increase physical activity and when to resume their normal lives. They were also uncertain about how to continue their medical treatment. Furthermore, the participants indicated that they did not always recognize their own resources on a concrete and experiential level.

3.4.4. Depressed, Transfixed Orientation. In this study, there were also some participants, who felt emotionally and physically powerless and described their life as "transfixed." They did not have the will, desire, or psychological power to deal with or change their situation. Lacking the courage to participate in social happenings, they stayed at homes. Their everyday life was apparently characterized by varied fears, anxiety, and unhappy thoughts. The interviewees, who seemed depressed, explained that they often experienced a fear of death or hoped for death and wanted to give up everything. They also felt anxious if they were compelled to concentrate on new or strength-demanding issues. Three of the working-aged participants in this study, one woman and two men, reported feeling so hopeless, depressed, and powerless that they did not think they would return to work.

3.4.5. Illness-Centered Orientation. In some cases, the experienced MI had apparently become the centre of the participants' life. Some of the men and women concentrated on their symptoms and waiting for the recurrence of the MI. They felt paralyzed or completely incapacitated and very dependent on their family members. Those especially, who suffered from heart failure as a result of the infarction,

seemed to have adopted a strong illness-centered orientation towards life.

A woman of 82 years woman reported how her life had been centered around her heart disease. Since the infarction, she had suffered from chest pain and shortness of breath almost daily. The symptoms were so severe that she was unable to concentrate on anything else.

Sometimes illness becomes a means to gain more attention from family members, resulting in the family's activities becoming centered around the participant's illness.

A symptom can also represent a concrete sign of life for the patient—because they can still feel the symptom.

3.4.6. Protective-Secretive Orientation . It was very common even 12 months after the myocardial infarction that the men and women experienced a strong need to protect their family members from the seriousness of their illness. Over 50% of them tried to hide their symptoms and did not discuss them with their spouses. Sometimes this seemed to result in interaction problems and lack of confidence and trust:

I am trying to hide my pain from the wife, but I think she suspects that I do not tell everything. I do not want to make her worry, on the other hand this hiding may damage our mutual interaction, we are not so forthright and open like we used to be.

4. Discussion

The results of this study reveal great differences in patients' dynamic and individual coping processes after a myocardial infarction. The comparison of the same participants' situation 4 and 12 months after the MI reveals what can be described as a continuum of coping. The participants, who had accepted the reality of having suffered a cardiac infarction and had dealt with their subsequent emotions and fears by 4 months after the MI, were balanced and serene also at 12 months. Their coping can be seen as representing either a future-focused or a coherent and harmonic orientation. The future-focused orientation is, perhaps naturally, more typical of patients who are still active in working life. The sense of coherence, as shown by Antonovsky (1993) [47], an internal locus of control, and sharing thoughts and problems with family members (social support) seem to guide the direction of this kind of positive coping processes. Adopting health-promoting behaviour is also dependent on the patient's self-efficacy, sense of coherence, and motivation and readiness to change.

In contrast to the patients described above, the interviewees, who were anxious or depressed or closely observed their symptoms four months after their infarction, still represented a depressed, transfixed, or illness-centered orientation at 12 months. These patients had less physical and emotional resources to deal with their changed situation, and they did not rely on their coping with the MI. Many of them denied the seriousness of the disease or suffered from various fears, shame, and guilt. These men and women had a tendency to observe their physical symptoms and to anticipate another

infarction. There was no evident association between the type of MI and coping orientation.

An important finding of this study was that the patients did not have time to become fully aware of their new situation during the short hospital stay, which makes it demanding for the medical and nursing staff to identify patients prone to depression or denial. Awakening to reality 2–4 months after their discharge, the patients would then need support from nursing staff and doctors in their coping. Fleury et al.'s study (1995) has also shown that the coping process may include individual questioning, patterning, feedback, and repatterning that leads to balance over time [46]. According to our study it is not always possible to achieve a balance even 12 months after MI.

Another problem calling for attention concerns the interaction between patients and their family members. Even after a year following the infarction, many patients seem to conceal their situation to protect their families or find it difficult to discuss their illness because of experienced guilt or shame. Spouses, on the other hand, are often aware that everything is not in order and may become overprotective, inadvertently increasing the patients' sense of inferiority or feeling that they are not relied on anymore. The lack of open communication can thus increase stress and lead to further emotional problems. In this study, these patients' attitude at 12 months was termed "protective-secretive orientation." The findings are similar to the results of earlier studies. For example, Svedlund and Axelsson (2000) found that it is typical of myocardial infarction patients to feel ashamed for being weak [15]. Earlier studies have also proposed that spouses' overprotectiveness can reduce the patient's independence and cause tension between family members [5].

The study did not produce much knowledge about whether the work of nursing staff influenced the patients' coping in a significant manner. This does not mean that the possibility of such an influence could be excluded.

Based on the results, a nurse-led counseling and discussion intervention is recommended for MI patients approximately 4 months following the infarction. At this point it would be easier to identify those patients, who still deny the seriousness of the situation, do not know how to deal with the disease-related issues or emotions, or suffer from depression and emotional exhaustion. The discussion would also provide an opportunity to help the patients become conscious of their individual disease control and life management resources.

Another recommendation based on the findings is a more family-centered approach to nursing patients with MI. The family should be involved at an early stage, already in hospital, to help family members support the patient's coping. It is equally important to engage the family in the suggested counseling and discussion interventions at 4 months.

5. Conclusion

Coping with a myocardial infarction is a long-term dynamic process of dealing with varied emotions and adjustment

needs. Coping is threatened, if the patient denies the seriousness of the situation, suffers from depression and emotional exhaustion, or if there are serious problems in the interaction with family members. This study stresses the importance of recognizing the patient's depressive state of mind and the psychological aspects which affect family dynamics. It is important to arrange an updating education for all health care personnel on the recognition of patients' depressive symptoms. It would be important to arrange meetings with counseling nurses specialized in myocardial infarction 4 months after the myocardial infarction. During this meeting the nurse could give empowering counseling for the patient and try to find out if the patient still suffers from denying the seriousness of the situation or depression. These empowering counseling meetings could be arranged in the hospital, and it would be important to assess during these meetings whether the patient also needs the psychiatric help. It would be important to take the patient's spouse along to these meetings. A more family-centered approach involving a posthospital counseling intervention is recommended.

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Review Article

Self-Management in Daily Life with Psoriasis: An Integrative Review of Patient Needs for Structured Education

Gitte Susanne Rasmussen,¹ Helle Terkildsen Maindal,² and Kirsten Lomborg²

¹ Department of Dermatology, Aarhus University Hospital, 8000 Aarhus, Denmark

² Department of Public Health, Aarhus University, 8000 Aarhus, Denmark

Correspondence should be addressed to Gitte Susanne Rasmussen, gittramu@rm.dk

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The aim of this integrative review is to identify and discuss patient needs for education to support self-management in daily life with psoriasis. As psoriasis increasingly gains recognition as a serious chronic autoimmune skin disease with long-term impairment on the life course, and not mainly a cosmetic problem, nurses are highly challenged to develop efficient education to support patient self-management. The paper includes five stages: (1) problem identification, (2) literature search, (3) data evaluation, (4) data analysis and synthesis, and (5) presentation, based on theoretic scaffolding around the concept “need.” Nineteen of 164 original papers within nursing, medicine and psychology, and reflecting patient perspective were included. To capture the patients’ cultural understanding of the implications of the disease and care, we developed an interlevel model indicating that self-experienced burden of disease and its visibility, personal conditions such as illness perception, and the patient’s age at onset time are high-impact factors that should be addressed in future structured patient education programmes. The research on patient needs has hitherto focused on adults, but the problems and vulnerability associated with having a chronic and visible disease during adolescence must be acknowledged, and patient education initiatives designed for this young group are recommended.

1. Introduction

Psoriasis is a common chronic inflammatory immune-mediated skin disease characterised by red, thickened, and scaly skin. Approximately 2 per cent of the world’s population currently live with psoriasis, the prevalence appearing to be highest in Scandinavian countries and Northern Europe [1]. Recent research reports that the onset of the disease occurs before the age of 16 in 27–45% of the cases and before the age of 20 in more than 50% of the cases [2, 3]. The course of disease varies greatly, and treatment is often time-consuming and distressing [4].

The growing interest in psoriasis has underlined that the disease constitutes a substantial physical burden and may impact the patient’s life course in various ways. Numerous studies in the field of Health-Related Quality of Life have quantified the impact of psoriasis on daily functions and activities [5–8] as well as quality of life to an extent similar to other major diseases such as cancer, diabetes, and

cardiovascular disease [9]. It is commonly recognised that the stigma associated with visible skin lesions may lead to psychosocial adjustment problems [10, 11].

Psoriasis is not only a cosmetic problem for the patients. A recent review has reported an association between psoriasis and severe physical conditions such as psoriatic arthritis, cardiovascular disease, metabolic syndrome, and Crohn’s disease. In addition, life expectancy is reduced by several years in individuals with severe disease, mainly caused by increased risk of heart disease [12].

This new insight has resulted in an upcoming shift in the treatment of psoriasis, from exclusively treating a skin disease towards comprehensive disease management including early diagnosing, monitoring, and intervention. This shift has increased the focus on developing new interventions, and patient education is one of several initiatives that aim to motivate people to chronic disease self-management. Self-management is generally defined as the day-to-day activity

that an individual carries out to manage his/her long-term health condition. There is no gold standard definition of self-management within nursing science. The on-going discussion to clarify and develop this concept [13–18] emphasizes that self-management can be viewed from three perspectives: a process reflecting the patients perspective; a structure that reflects the perspective of the health professionals often described as educational activities; and a goal or an outcome for the patient, for example, to improve quality of life or maintain health or well-being. In accordance with the aim of this review it seems relevant to adopt the patient's perspective on the concept of self-management. The concept refers to the activities people undertake to create order, discipline and control in their lives. Self-management is an active and dynamic process of learning, trying and exploring the boundaries created by illness, and it fluctuates as life and illness itself presents new challenges ([15], page 265).

Despite increasing emphasis on the need for structured disease-specific patient education programmes in severe chronic illness [19], only a few studies on patient education in the area of psoriasis are available [20–24]. The research in this area has tended to focus on the importance of the physician-patient relationship to improve the patients' perceived control of the disease [20, 22] as well as information on psoriasis and treatment as a way to improve adherence to treatment, skin care [22, 24] and psychological relief [23]. One disease management programme focused on knowledge of the disease, patient skills training and psychological support [24], documenting improvements on disease severity, adherence to treatment and quality of life. Although the inclusion of psychosocial aspects is recommended in structured education programmes [5, 25, 26], one review [27] reported a lack of evidence of the effect of psychosocial interventions for individuals with visible differences including psoriasis.

With one exception, the above-mentioned studies reflect the health professionals' perspective of what is important in education programmes. Less attention has been paid to the patients' perspective and substantial educational needs in daily life. Linder et al. [22] identified hope of curability, perception of control and understanding from the physicians as valuable elements for the patients. Generally, the studies provide no clear recommendations related to content, pedagogical considerations, patient involvement, or outcome measures.

In nursing science, Thorne et al. have shown that patients depict a specific "world of disease" for each chronic disease—a cultural knowledge of the implications of the illness and the particular care for that world [19, 28]. This cultural knowledge greatly influences how information about the disease and health is received by patients and consequently should be taken into consideration when developing patient education. A similar viewpoint is reflected in a recent Danish Health Technology Assessment (HTA) about patient education [19]. The HTA recommends that the patients' experience of the specific nature, characteristics, and course of disease should be involved when developing new interventions. This means that a new intervention should focus on the needs of the patient, thereby ensuring patient-oriented criteria for success

as an important factor determining the content of the programmes.

To our knowledge, no studies have yet investigated the needs assessments related to patients with psoriasis. According to Bartholomew et al. [29], the initial process of needs assessment may include a systematic study of the scientific literature reporting on the discrepancy between what is and what should be, experienced by patients living with a problem like psoriasis. This discrepancy should be studied in relation to quality of life, health status, and factors that influence health and health risk. These factors include lifestyle, health behaviour and social behaviour, personal factors like self-care, coping and adaptation as well as family as part of the environmental factors.

Therefore, we designed an integrative review to gain insight into and achieve a comprehensive understanding of people living with psoriasis and their needs for patient education based on their perspectives. The review aimed to answer the question: which factors related to the disease and the course of disease may, according to the existing literature, impact patients' needs of structured patient education to support self-management of psoriasis in daily life?

2. Methods and Materials

An integrative review of the literature was conducted, applying the strategy for this method described by Whittemore and Knafl [30, 31]. The method was chosen because qualitative and quantitative studies can be combined within different disciplines. Consistent with this approach, the review included (1) problem identification (stated previously), (2) literature search, (3) data evaluation, (4) data analysis and synthesis, and (5) presentation.

2.1. Literature Search. A search strategy was designed in cooperation with a research librarian. Searches were conducted in February 2010 and repeated in January 2011. The following databases: Bibliotek.dk (Danish), PubMed, Embase, CINAHL, and SveMed+ were searched for papers in English or in a Scandinavian language published between 2000 and 2010/2011. A complementary search in PsycINFO was conducted in September 2012. Variants of the following keywords were searched separately and in combination, adapted to the thesaurus of the database concerned: *psoriasis AND quality of life OR health status OR lifestyle OR health behaviour OR social behaviour OR family OR self-care OR coping OR adaptation AND research OR nursing research OR interview OR focus group OR qualitative research OR questionnaires OR survey*. Further references were searched for using reference lists in retrieved papers, and relevant nursing journals (Dermatology Nursing, Scandinavian Journal of Caring Science, Patient Education and Counselling, Chronic Illness) were checked to identify other relevant studies.

2.1.1. Selection Criteria. In addition to the main inclusion criteria mentioned above, further criteria were determined as they captured the focus of the research question. The papers should report on either the patients' perspective on

the impact of psoriasis on their lives or their support needs to be able to manage the illness in everyday life. The papers were excluded if they (1) reported on medical treatment using quality of life measures as well as the development of measuring instruments, unless the patients' perspective of the impact of disease or self-management was clearly stated, (2) included several groups of patients unless the results for the psoriasis group were reported separately, or (3) reported separately on psoriasis arthritis, as arthritis has a different impact on function, fatigue, and pain than is the case with skin symptoms and therefore gives rise to different needs related to joint protection.

2.1.2. Data Evaluation. The titles and abstracts of all studies identified by the search strategies were assessed for their relevance to data extraction. Those that immediately met the inclusion criteria were selected for more detailed examination. The full-text versions of these studies were then obtained for close reading. The full-text reading caused the exclusion of papers that were not considered relevant to this study, for example, papers reporting on telephone consultancy methods or different models of illness and their suitability in medical practice, socioeconomic impact of disease, association between psychological variables and outpatient services. Due to the substantial diversity of the methodological approaches, we developed two quality criteria instruments according to recommendations by Polit and Beck [32] and Forsberg and Wengström [33] (see Table 1).

The instruments were developed for the qualitative and quantitative studies, respectively, enabling us to assess methods of research design, sampling, and conclusions. To prevent unnecessary complication of the analysis process, the quality of each included study was assessed as good or less good. Papers were included for final review if they generally met these criteria. A total of 770 papers were identified by key search terms, but most of these failed to meet all inclusion criteria (see Figure 1).

2.1.3. Data Analysis. According to the research strategy, each paper was carefully examined for data reduction, data display, data comparison, conclusion drawing, and verification [30]. The first phase of the data reduction classified the papers in terms of author, year of publication, country, research design, and disciplinary perspective. The disciplinary perspective was determined by the professional title of the first author and the name of his/her institution, and verified by web search if needed.

The second phase of the data reduction was performed according to aim, informants or population, data and measures, findings and results, and, finally, the authors' conclusion and discussion. For each paper, data relevant for the purpose of this study were extracted and organised in comparable frameworks. Thus, each primary source was reduced to a single page with similar data. Because of the fragmentation between the studies we found no heterogeneity of the above-mentioned variables, which is why an overall comparison of the studies would not make sense for the

purpose of this study. We then proceeded inductively and developed a coding scheme where the objective of the coding is in the realm of themes and ideas [35]. In this approach, the objective of the coding is to develop a broad-based code, for example, physical symptoms from the skin in order to create collection of accounts, for example, pain, itching, scaling, discomfort, or not well at all, from which we could begin considering whether the phenomenon refers to illness, the trajectory, the treatment, the life phase, and so forth. The coding included 13 themes of significance to patient needs (see Table 3). The themes were divided into three separate clusters, and each paper was examined with the purpose of verification of coherence with the clusters (see Table 3.) To establish a clear connection between the clusters, each of the three clusters was further explored using the original data material to identify differences, similarities, and internal relationships. This in-depth analysis was synthesised into an interlevel model ([36] page 146) with the intention to present the complex interaction of high impact factors at different (psychological, social, and biological) levels related to the disease and course of the disease that should be addressed in future structured patient education programmes in order to support the patient's self-management in daily life.

3. Findings

Nineteen papers were included for final review, representing different countries: Norway, UK, Poland, The Netherlands, USA, Sweden, South Africa, Australia, and three disciplines: medicine, psychology, and nursing. Seven papers represented qualitative studies, while 12 papers represented quantitative studies. All selected papers address, in different ways, the patients' experience of discrepancy between how life is lived with psoriasis and how life should be lived. The purpose of the studies fall into two main groups: (1) to investigate the perspective of patients and/or families/partners on the impact or the burden of disease, and (2) to investigate the association between several different factors that influence the patients' ability to manage the disease in relation to function, well-being, and quality of life.

Different theories were applied in the studies, including Lazarus' & Folkmann's coping theory, Leventhal's common-sense model as well as various theories on pain, self-concept, stigma, illness acceptance, and body phenomenology. A wide selection of measuring instruments were used, with Psoriasis Area and Severity Index (PASI) and Psoriasis Disability Index (PDI) being the most recurrent.

Three main clusters of high-impact factors were (1) disease-specific factors constituted by visibility of disease, onset time and the fluctuating nature of disease; (2) self-experienced burden of disease, where the physiological, psychological, and social self-experienced burden of disease were the most frequent themes in most studies; (3) personal factors with themes like illness perception, coping strategy, gender, age, family, and partners. Table 3 shows the distribution of the selected studies on the three clusters (numbers indicate reference number in this paper). Several studies appear in more than one cluster.

TABLE 1: Criteria for assessment of identified papers.

Qualitative papers	Quantitative papers
Problem stated unambiguously?	Statement of the problem?
Ethical problems reflected?	Identified aim, hypothesis or research question?
Identified aims congruent with methodology and methods for data collection and analysis?	Sufficient description of the population and transferability into Danish context?
Sufficient details of the informants and settings?	Adequate description of measures?
Method for data collection described?	Adequate description of data collection?
Sufficient detail of the process of analysis provided to ensure accordance with selected method?	Sufficient description of data analysis?
Results presented systematically?	Findings adequately summarised and answering research question?
Conclusions reflect results from the study and relevance for practicing nursing in a Danish context?	Generalisability of the findings for Danish nursing practice and discipline?

Subject headings and combinations:
 Psoriasis
 and
 quality of life or health status or lifestyle or health behaviour or social behaviour or family or self-care or coping or adaptation
 and
 research or nursing research or interview or focus group or qualitative research or questionnaires or survey.
 Limits: 2000–2010/2011. English or Scandinavian languages. Peer-reviewed journals.
 Databases: PubMed (441), CINAHL (144), Embase (77), SweMed+ (28), PsycINFO (80), Bibliotek.dk (0).

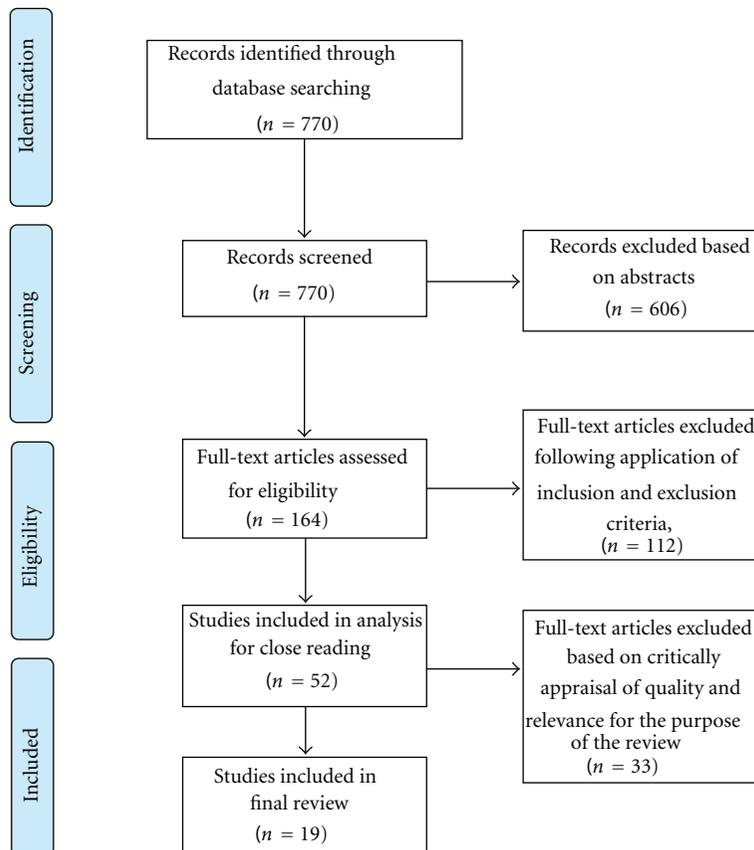


FIGURE 1: Flow diagram of the search process, adapted from Moher et al. [34].

TABLE 2: Key data, selected papers.

Author, Year, Country, Discipline, Design	Aim	Informants, Population	Data, Measures	Findings, Results	Author conclusion and discussion
Wahl et al., 2000. Norway. [37] Nursing. Cross-sectional.	To assess health-related quality of life among patients with psoriasis and to compare these estimates with population norms.	283 patients treated at 3 dermatology departments in the eastern part of Norway. Gender: 57% M, 43% F. Mean age: 47 years. Control subjects 3,500 of the general. Norwegian population, mean age: 45 years.	Short Form 36	After adjustments had been made according to age, gender, educational level and marital status, it was seen that psoriasis patients reported poorer health-related quality of life in all 8 conceptual domains compared to norms from the general Norwegian population. The largest difference was found on the role limitation scale—emotional scale.	The burden of psoriasis is significant at the emotional life domain. This domain deals with problems in relation to work or other regular daily activities as a result of any emotional problems, such as feeling depressed or anxious. The patients' own assessments of symptoms specifically related to psoriasis are related to their evaluation of health-related quality of life.
Wahl et al., 2002. Norway. [38] Nursing. Qualitative.	To present results from a qualitative study that focuses on patients with psoriasis, their experience of living with the disease, and its psychological and social impact.	22 hospitalized patients with severe disease, that is, more than 30% of the body affected. Gender: 10 M, 12 F. Age: 20–80 years (majority 40–60 years). Diagnosed with psoriasis for more than 3 years.	Transcribed interviews.	Bodily suffering emerged as the core category, with the following subcategories: (i) The visible body (ii) Social vulnerability (iii) Staying on an even keel (iv) An all-consuming disease Many different aspects and nuances are related to the patients' body experiences, for example, concern that their body seemed offensive, unclean, infectious, disgusting, leprous, ugly unattractive, strange or different. The wish to keep the disease secret and to camouflage it is a very prominent aspect of living with psoriasis. Feelings of despair, vulnerability and hopelessness are related to living with psoriasis. Psoriasis can control every aspect of the patients' lives.	Patients' experience of living with psoriasis includes bodily suffering, changed self-image, the perception of being stigmatised, and social isolation. For some people, the body can no longer support the positive social function. Psoriasis is described as an enemy that saps the patients' spark and energy during bad periods.
Fortune et al., 2002a. United Kingdom. [39] Psychology. Cross-sectional.	To examine strategies for coping in patients with psoriasis and investigate whether they differ compared to normal controls and patients with other major medical diseases.	250 patients attending psoriasis specialty clinic at Hope Hospital. 27% with severe psoriasis. Gender: 53% M, 47% F. Age: 35–51 years. 60 healthy control participants. Published COPE scores from other medical diseases.	PASI. PDI. COPE	Across medical conditions, patients showed remarkable similarity in the type of coping strategies used. The most frequently used coping strategies were acceptance, planning, active coping and positive reinterpretation. Patients with psoriasis were using social support strategies less frequently than controls.	Illness brings with it a generic form of coping that requires shaping to fit the specific demands of specific illnesses like psoriasis. Many of the difficulties experienced by patients with psoriasis are so demanding that they outstrip the coping resources of the patient, the family or social network. More research is needed on how to make coping more efficacious and particularly on how the family may be assisted in this respect.

TABLE 2: Continued.

Author, Year, Country, Discipline, Design	Aim	Informants, Population	Data, Measures	Findings, Results	Author conclusion and discussion
Fortune et al., 2002b. United Kingdom. [40] Psychology. Cross-sectional.	To investigate whether coping and alexithymia should be given significant consideration in the conceptualization of patient's adjustment to psoriasis, or whether the cognitive model (illness perception) of the condition held by patients is adequate on its own.	225 patients from Dermatology Centre at Hope Hospital, Salford. Gender: 52% M, 48% F. Age: 18–75 years. Mean age: 43 years.	PASI PLSI PDI PSWQ HADS IPQ Alexithymia Scale COPE	Cognitive psychological factors, mainly illness perception and to a lesser extent coping, appear to be more important for the patients' quality of life and psychological well-being than clinical severity.	The study emphasizes the importance of recognizing that the onset of a chronic condition brings with it a range of difficulties that may vary considerably in their nature and severity as perceived by the patient. Importance of cognitive factors represents a move towards more multidisciplinary model of patient care.
Richards et al., 2004. United Kingdom. [41] Psychology. Cross-sectional.	To investigate the representation of psoriasis symptoms in psoriasis patients and their healthy partners, and to examine how their differences in beliefs about psoriasis may be associated with adaptive outcome in terms of anxiety, depression, and worry.	58 patients with chronic plaque psoriasis and their partners, recruited either from specialty clinic, dermatology outpatient clinic or inpatient ward setting. 49% M, 51% F. Mean age: 44 years; Mean duration of psoriasis: 18 years.	SAPASI IPQ-R HADS PSWQ	Patients with psoriasis had significantly higher levels of anxiety, depression and worry compared to their partners. The study indicated that divergence in patients' and partners' beliefs about emotional impact of psoriasis and chronicity of timeline accounted for statistical variance in depression for partners.	The study offers an insight into the way in which divergence, in terms of the way psoriasis is perceived by patients and their partners, may have an impact on psychological and clinical outcome. Moreover, the results illustrate the importance of concordance between the patients' and partners' models of psoriasis in relation to adjustment, and highlight the need to consider and collaborate with both patients and their partners in managing the challenging condition.
Jankowiak et al., 2004. Poland. [42] Nursing. Cross-sectional.	To determine the need for health education among patients with psoriasis through the determination of gaps that most frequently occur in this kind of knowledge.	149 patients. Gender: 45% M, 55% F. Age: 13–78 years; mean age 41 years.	Questionnaire based on the PDI.	The study illustrated, among other things: (i) 54% reported stress as a cause while 43% were unable to report any factor causing the disease.	Patients with psoriasis need to expand their knowledge about the disease and self-care methods. The largest knowledge deficit observed were the factors causing the disease. There is a need for individualized health education programmes.
O'Leary et al., 2004. United Kingdom. [43] Psychology. Cross-sectional.	To assess causal beliefs in a psoriasis population and to examine the link between these attributions and mood, quality of life, and health status. To measure perceived stress and examine the relationship between psychological well-being and psoriasis severity.	40 patients from an outpatient skin clinic and 101 from the Psoriasis Association. Gender: 58 M and 83 F. Mean age: 45 years (females were significantly younger than males). Mean duration of disease: 23 years.	PSS PDI SAPASI IPQ-R HADS	The most commonly endorsed causes were "stress/worry". More than 60% of the sample scored above the scale midpoint for "stress/psychological" indicating a strong causal belief in this factor. Levels of perceived stress, whilst strongly associated with mood and quality of life, were not associated with psoriasis severity.	A large proportion of people with psoriasis believe that stress is a causal factor in their illness. This belief was associated with poorer psychological well-being and the perception that psoriasis has a large emotional impact. Patients with psoriasis may need cognitive-behavioural interventions, which would allow individuals to identify their beliefs about their psoriasis and their medication and the impact that these have on their subsequent well-being and behaviour.

TABLE 2: Continued.

Author, Year, Country, Discipline, Design	Aim	Informants, Population	Data, Measures	Findings, Results	Author conclusion and discussion
Fortune et al., 2004a. United Kingdom. [44] Psychology. Prospective.	To investigate whether, and to what extent, improvement in the clinical severity of psoriasis induced by photochemotherapy with psoralen plus ultraviolet A translates into meaningful changes in beliefs about psoriasis, coping, stress or disability.	72 patients with psoriasis referred for PUVA treatment. Gender: 45 M, 27 F. Mean age: 42 years; duration of psoriasis: 2–50 years. Response rate: 100.	PASI PLSI PDI PSWQ HADS IPQ COPE Scale	The study reported that the medical management of psoriasis has demonstrable effects on disability and psoriasis-related stress experienced by the current sample of patients, but not on levels of distress, beliefs about psoriasis or on the coping strategies used by patients.	The findings imply that clinical clearance of psoriasis is not sufficient to bring about changes in patients' distress. Unlike disability, distress in patients with psoriasis is possibly linked to the cognitive aspects of a patients' world view rather than to its more behavioural aspects. To minimize psychological distress and physical severity of the disease, patients with psoriasis may need multidisciplinary treatment programmes to challenge and change unhelpful beliefs about the condition, to develop and foster more appropriate coping responses.
Evers et al., 2005. The Netherlands. [45] Cross-sectional.	To examine whether generic physical, psychological and social factors relevant to patients with chronic diseases contribute to psychological distress in adults with psoriasis and atopic dermatitis.	128 patients with psoriasis and 128 patients with atopic dermatitis (aged over 16 years) from a dermatology clinic at University Medical Center, St. Radboud. Gender: 39% M, 61% F. Mean age: 48 years; mean duration of disease: 18 years.	Skin status assessed with a nine-item scale. Itching: four-item scale and VAS. Fatigue: VAS. IRGL. Disease Impact Scale. Illness Cognition Questionnaire. IRGL—Social Functioning Scale.	The study reported that higher levels of psychological distress were significantly related to physical symptoms of fatigue, a greater impact of disease on daily life, illness cognition of greater helplessness and less acceptance, less perceived support and a smaller social network.	The study indicates that at least 30% of the patients suffer from a higher level of psychological distress. Higher levels of fatigue, illness cognitions of greater helplessness and less perceived support significantly contribute to distress in these patients. The study indicates that patients with psoriasis could possibly benefit from multidisciplinary treatment options that focus on fatigue reduction (focusing on sleep disturbance, rest-activity balance), changing patients' pessimistic and helpless attitudes towards their disease by improving patients self-efficacy in coping with disease, and mobilizing social support from significant others.
Wahl et al., 2006. Norway. [46] Nursing Cross-sectional.	To characterize how hospitalized patients coped with psoriasis and eczema during exacerbation of the disease in the period prior to admission to the dermatology ward, and to investigate the relationship between coping and quality of life.	146 hospitalized patients with psoriasis. Gender: 69 M, 76 F. Mean age: 49.5 years. Mean duration of psoriasis: 19.1 years.	JCS. DLQI-N. The Perception of Living with Disease.	The results indicate that optimistic, belief-in-oneself and confrontational strategies are most frequently used among patients who are admitted to the dermatological ward for treatment. Use of confronting strategies is related to better quality of life. Duration of illness is significantly related to supportive coping strategy and belief-in-oneself. The longer one had the disease, the more often one used the belief-in-oneself mode. Women and younger people use emotional coping strategies more often than men and older people.	It appears that illness results in a generic form of coping that may require shaping to fit the individual demands of diseases like psoriasis, and that patients with psoriasis tend to use significantly less active coping strategies. Furthermore it seems that patients who have lived and functioned longer with psoriasis may have acquired more individual knowledge concerning the illness, thereby making them less dependent on support from others to cope with problems related to the disease. The findings highlight the complex features of the patients' psychological experiences of psoriasis and underline the need for integrating psychological interventions into standard care protocols.

TABLE 2: Continued.

Author, Year, Country, Discipline, Design	Aim	Informants, Population	Data, Measures	Findings, Results	Author conclusion and discussion
Unaeze et al., 2006. USA. [47] Medicine. Prospective.	To examine changes in specific aspects in which psoriasis may impact individuals over time, and to determine sociodemographic and clinical characteristics associated with HRQOL at baseline 1993 and with change in HRQOL over time.	867 patients completed questionnaire in 1993. 484 patients completed questionnaire in 2004 Gender: 62% M, 38% F. Mean age: 53 years (2004).	IPSO.	<p>Responses to items assessing the impact of psoriasis on social aspects of HRQOL such as social activities, holiday or travel plans, and making new friends were generally stable.</p> <p>Over a period of more than a decade, impairment owing to psoriasis-related physical appearance decreased significantly (e.g., embarrassment/shame, unattractiveness, feeling like an outcast, which is among the worst aspects of psoriasis for the majority of patients).</p> <p>(i) More than 70% reported psoriasis having an overall impact on their lives. The impact was greater with involvement of feet, armpits, genitals and hands.</p> <p>(ii) 48% of reported disability was accounted for by problems related to activities of daily living, especially relating to washing and changing clothes, the need to bathe more frequently, sporting activities, and problems with sleep.</p> <p>(iii) 50% report the fact that therapy is time-consuming as the most troublesome aspect of treatment, followed by ineffectiveness.</p>	<p>The overall psychosocial impact of psoriasis on patients HRQOL decrease over time.</p> <p>The results suggest that chronic skin disease may become less burdensome compared to other health problems that increase with age.</p>
Dubertret et al., 2006. Europe. [48] Medicine. Cross-sectional.	To explore the patients' perspective of psoriasis on their lifestyle and well-being and to gain insight into effectiveness and satisfaction with current available therapies for psoriasis.	18,386 patient association members in seven European countries (Belgium, the Czech republic, Finland, France, Germany, Italy, and the Netherlands). Gender: 49% M, 51% F. Mean age: 30 years; Mean duration of psoriasis: 23 years. Response rate: 36.	Self-administered questionnaire developed in collaboration with EUROPSO (European Federation of Psoriasis Patients Associations) and the NPF (National Psoriasis Foundation). PDI.	<p>The following themes emerged:</p> <p>(i) Marked by Visibility</p> <p>(ii) Adjustment</p> <p>(iii) Routinization</p> <p>(iv) Quality of life</p> <p>The most distinctive feature among both men and women, and with no variation between genders, was the feeling of being marked by the visibility of psoriasis in different social situations.</p> <p>Coping strategies did not differ among gender. The participants lived their lives with psoriasis in acceptance and/or restrictions, turning it into a routine in everyday life, which influenced the quality of life.</p> <p>Acceptance as well as routinization of the marking process developed with age, whereas concealing and avoiding were strategies used at all ages.</p>	<p>It is evident from this survey that patients with psoriasis suffer from significant impairment of their QoL.</p> <p>The perceived severity of disease is associated with the involvement of body area. It seems that self-reported severity of disease is associated with the overall impact of disease.</p> <p>The study enhances the understanding of complex interrelations between QoL impairment, psychological stress, disease severity assessment and patients' educational needs regarding their disease.</p>
Uttjek et al., 2007. Sweden. [49] Medicine. Qualitative.	The main issue is to find out how psoriasis affects the individual's everyday life, and if there is any variation between genders.	18 patients were selected from a population of a previous study with regard to gender, place of residence, and in relation to three district health care centres in Västerbotten. Age: 37–74 year, mean 58 years	Transcribed interviews.	<p>The worst situations occurred when patients were young and after onset of psoriasis, and included the visibility, the feeling of being marked, the struggle to conceal the disease and the fear of being rejected.</p> <p>Being with family or friends or being of some use contributed to good quality of life.</p> <p>The burden of being marked by the visibility was like an ever-present shadow for most of the patients and lead to restrictions in everyday life.</p> <p>Adolescence was found to be a tough period with psoriasis.</p> <p>As long as marking and discretion processes are going on in society, it is important to provide persons with psoriasis adequate help and support to not restrict their everyday life.</p>	<p>The worst situations occurred when patients were young and after onset of psoriasis, and included the visibility, the feeling of being marked, the struggle to conceal the disease and the fear of being rejected.</p> <p>Being with family or friends or being of some use contributed to good quality of life.</p> <p>The burden of being marked by the visibility was like an ever-present shadow for most of the patients and lead to restrictions in everyday life.</p> <p>Adolescence was found to be a tough period with psoriasis.</p> <p>As long as marking and discretion processes are going on in society, it is important to provide persons with psoriasis adequate help and support to not restrict their everyday life.</p>

TABLE 2: Continued.

Author, Year, Country, Discipline, Design	Aim	Informants, Population	Data, Measures	Findings, Results	Author conclusion and discussion
Eghlileb et al., 2007. United Kingdom. Medicine. Qualitative.	To identify the various ways in which the lives of relatives and partners of people with psoriasis are affected by the disease.	63 patients with psoriasis and their relatives or partners from a dermatology outpatients department of the University Hospital of Wales. Gender: 40 F 23 M. Age: 20–80 years. Mean age: 51 years.	Transcribed interviews and an open-ended postal questionnaire.	The impairment of relatives' lives were assigned to six different domains: (i) Treatment (ii) Psychological impact (iii) Social disruption (iv) Sport and leisure limitations (v) Daily activities (vi) Personal relationships	Psoriasis not only interferes with the daily lives and social functioning of patients with psoriasis, but also has a major impact on QoL of their relatives and partners. The study indicates the need to develop appropriate new care strategies for patients with psoriasis, also including their partners and families.
Watson and de Bruin 2007. South Africa. Psychology. Qualitative. Disease-specific factors. Self-experience burden. Personal factors.	To describe the lived experiences of men and women with psoriasis and how their perceived experiences impact the various dimensions of their self-concept.	7 patients with psoriasis. Gender: 3 M, 4 F. Age: 29–65 years. Illness duration: 11–60 years.	Patients' detailed descriptions of their perceptions and descriptions of their intrapersonal and interpersonal self as a person living with psoriasis.	The findings are synthesized in themes shared by all participants: (i) Impact of psoriasis on self-concept evaluation. (ii) Implications of treatment on the self-concept experience. (iii) Coping methods to enhance the self-concept. (iv) Meaning-making of the psoriasis self-concept experience. Psoriasis is described as invasive, intrusive, violating and disgusting, and is defined as an assault on the physical self that was unsightly, painful, embarrassing and humiliating. Psychological adapting to psoriasis was described as a journey of emotional and physical turmoil in the reconstructing of self.	Evident from the study is the tremendous power yielded by psoriasis in the arena of self-concept change. According to the participants, psoriasis is life changing radically, altering the self and the participants' being in contact with the self and others. Psoriasis knows no boundaries in its assault on the physical body. The experience of living with psoriasis leaves the patient feeling entrapped within an unfamiliar body Being young and single with psoriasis is described as devastating.
Amatya and Nordlind 2008. Sweden. Medicine. Qualitative.	To assess patients' perspective of pruritus in psoriasis vulgaris of plaque type.	20 patients selected from outpatient clinical records of the Department of Dermatology, Karolinska University Hospital. Intensity of itch > 4 by VAS. Gender: 7 M, 13 F. Age: 30–55 years. Mean disease duration: 17.7 years.	Transcribed interviews.	Pruritus is a common phenomenon in patients with psoriasis. Patients regard themselves as able to discriminate between pain and pruritus. Itch rather felt like pins and needles, and is characterized as burning and irresistible. Unbearable pruritus affects quality of life, that is, not taking part in general social activities and feelings of depression.	The study indicated that pruritus may be severe and affect quality of life in psoriasis patients.

TABLE 2: Continued.

Author, Year, Country, Discipline, Design	Aim	Informants, Population	Data, Measures	Findings, Results	Author conclusion and discussion
[53] Magin et al., 2009. Australia. Medicine. Qualitative.	To investigate the psychological co-morbidities in psoriasis in patients from general (family) practice and specialist practices.	29 patients with various disease duration and disease severity. Gender: 11 M, 18 F. Age: 25–71 years.	Transcribed interviews.	A schema of the interactions of psoriasis and psychological co-morbidities is developed with individual themes: (i) Appearance and self-image, self-esteem and self-identity. Subjects often expressed a belief that they were defined by their skin and reported diminished self-esteem. (ii) Behavioural consequences: Social interactions and lifestyle were circumscribed by avoiding activities leading to embarrassment and shame, caused by a sense that others were scrutinizing and judging character or intrinsic world.	Psychological sequelae are complex and encompass a range of psychological morbidities. Symptoms of anxiety and depression were often causally linked by respondents to experiences of embarrassment or shame or to the socially limiting effects of behavioural avoidance. This was overt in cases where children with psoriasis were teased or taunted. The study indicates that psychological sequelae are more common in females, but males are also markedly affected including concerns regarding appearance and social and sexual attractiveness. Patients with psoriasis need social support and a patient-centered approach to management, emphasizing coping strategies, patient education and subsequent involvement in management decisions might reduce psychological co-morbidity.
[54] Globe et al., 2009. USA. Medicine. Qualitative.	To explore psoriasis patients' perception of the impact of psoriasis.	39 patients identified by general practitioners participated in 5 separate concept elicitation focus groups. 4 groups included 31 patients with severe psoriasis, and 1 group included 8 patients with mild psoriasis. Gender: 17 M, 22 F.	Transcribed interviews.	All participants reported itch as an important impact on everyday life. The affective dimensions of itch were described as unbearable, worrisome, bothersome and annoying. The sensory dimension of itch was described as burning, stinging, and crawling like ants. Itch symptoms affected sleep quality, concentration and regular physical activity. Some patients reported missing work or school because of itch symptoms.	From the patients' perspective, itch is one of the most important symptoms of psoriasis contributing to diminished health-related quality of life in patients with both mild and severe disease. The sensory dimension of itch is a significant predictor of depression, distress and sleep impairment. There is a need for assessment of itch in clinical practice to help patients with this troublesome symptom.
[55] Ljosaa et al., 2010. Norway. Nursing. Cross-sectional.	To investigate (i) prevalence and characteristics of psoriasis-related skin pain and discomfort, (ii) evaluate differences in demographic/clinical characteristics among patients with or without skin symptoms, and (iii) to explore symptoms characteristics.	139 patients recruited prior to a consultation at the inpatient and outpatient dermatology units at a university hospital in Oslo. Gender: 44% M, 56% F. Mean age: 51 years.	Co-morbidity (SCQ-18). Prevalence of skin pain and skin discomfort. BPI. PQAS. PASI.	The study showed that (i) 41.7% of patients reported skin pain. (ii) 36.7% of patients reported skin discomfort. Significantly higher percentages of patients with pain (88–94%) reported that their symptoms interfered with mood, work, sleep, and relations with other people compared to patients with discomfort. Patients with pain reported significantly higher severity on items like enjoyment of life and daily activities.	Findings from this study suggest that psoriasis-related skin pain and skin discomfort may be a larger problem than previously estimated.

TABLE 3: Themes, clusters and verification of findings.

Theme	Cluster	Verification
Visibility of disease		
Onset time	Disease-specific factors	[37, 38, 45, 47–49, 51–54]
Fluctuating nature of disease		
Physical symptoms: itch, pain, discomfort	Self-experienced burden of disease (physical)	
Bodily suffering		
Disease impact on self-concept		
Psychological impact of disease	Self-experienced burden of disease (psychological)	[37, 38, 40, 41, 44, 45, 47–55]
Disease as a psychological burden		
Disease impact on family and partner	Self-experienced burden of disease (social)	
Disease impact on daily life		
Personal coping strategies		
Personal factors, illness perception	Personal factors	[37–46, 49, 51, 53]
Personal factors, partner, family and network		

3.1. Disease-Specific Factors

3.1.1. Visibility of the Disease. Visibility is distinctive for the nature of the disease and significantly influences how patients manage their disease. In a trans-European study, 48% of the patients reported that their quality of life was affected in relation to physical appearance [48]. For both men and women, the greatest difficulty of living with psoriasis was the sense of being marked by the disease [38, 49]. Such experiences are described as a sense that other people tend to scrutinize and judge them, their character and inner world according to the appearance of their skin [53], or more correctly their own perception of this appearance [38]. In particular, the patients are worried that they may be perceived as having low hygienic standards, or that the disease is contagious [53]. This perception is especially distinct in patients who have experienced teasing and bullying during childhood [49, 53]. The sense of being marked by the visibility of their disease was like an ever-present shadow for the majority of the patients, especially in out-groups and public places [49]. Visibility emerges as a general theme throughout the material to such an extent that it appears in all three clusters.

3.1.2. The Fluctuating Nature of the Disease. The disease is characterized by its fluctuating nature and thereby a fluctuating course of disease/trajectory. Patients experience their disease as a physical, tumultuous journey while the disease expands and one flare-up is followed by another [51], or as an eternal cycle where the patient at one time can function normally and the next moment finds himself almost isolated from the world. A symptom-free period can be experienced like being released from prison [38]. This fluctuating course of disease means that, when an accumulated loss of earlier self-perception cannot be restored and replaced by a new image, the patients may come to experience reduced self-esteem and self-confidence [38, 51].

3.1.3. The Significance of Onset Time. A number of studies suggest that the patient's age at onset time for the disease

is perhaps the one factor with the greatest influence on the course of the disease [49, 53]. This is probably linked up with the fact that the process of being marked begins very early. The sense of being young and single and suffering from an “ugly” disease like psoriasis is described as devastating. When they looked back, the patients related that, in their youth, they looked on their body with disgust and assumed that nobody would ever wish to be their partner [51].

One study points out that, in addition, the time immediately following onset is a significant factor for the course of disease [51]. This period can be filled with the fear of having to live with the disease and for the ensuing consequences. The understanding of the chronic nature of the disease and that one cannot be cured, either by one's own effort or with the help of others, is described as very depressing. These worries were felt most strongly by patients below the age of 30 and were expressed as thoughts of having no partner, job or close friend to rely on [49].

The studies show that fundamental conditions such as the visibility and fluctuating nature of the disease are of crucial importance to patients, not least if the onset occurs during adolescence.

3.2. Self-Experienced Burden of Disease. Patients with psoriasis suffer considerably from the impact of the disease on daily life as regards general health-related quality of life, disease-specific quality of life as well as quality of life as lived experience [37, 47–49]. In a Norwegian study, the patients reported a reduced general health-related quality of life within all of eight conceptual domains including: self-reported general health, physical functioning, bodily pain, mental health, physical role limitations, emotional role limitations, vitality, and social functioning [37]. Among European patient association members, 70 per cent of the respondents stated that the disease generally impacted their lives [48]. One study shows that patients, even after having lived many years with the disease, experience that psoriasis impacts their daily lives [49]. The studies distinctly indicate that the clinical severity of the disease has no causal relation to how patients experience the burden of their disease and

the impact on their quality of life. It is the self-experienced severity of symptoms and outbreaks that constitute a key factor in relation to the course of disease and are significant for how well patients manage to live with their disease [37, 48].

3.2.1. *Physical Burden of Disease: Itch, Pain, and Discomfort.*

Research in this field has mainly been focusing on patient perspective on the psychosocial burden of psoriasis rather than on how physical symptoms affect daily life. However, a frequently cited study on patients suffering from severe disease indicates that the disease is associated with an extensive experience of bodily suffering, physically described as pain and reduced mobility [38]. Recent studies indicate that the physical burden represented by itch [52, 54] as well as skin pain and discomfort [55] is likely to be more serious than has previously been assumed in cases of severe and mild disease.

In particular, several studies report itch to be one of the most unpleasant and irksome symptoms related to psoriasis. Itch is described as unbearable, worrisome, bothersome, and annoying, and the sensory dimension is described as burning, stinging, and crawling [54]. The sensory experience may be severe and may affect power of concentration, daily activity, physical activity, sexual activity, and sleep [52, 54]. One of the studies accentuate the need for the development of instruments that are capable of measuring itch in clinical practice, in order to better help the patient group manage this severe problem initially by acknowledging the problem itself [54].

The treatment as such is reported as bothersome and ineffective [48] and is experienced as unpleasant, painful, and draining the patients of time and energy. This applies to daily home treatment, hospital or clinic treatment as well as side effects such as itch, pain, smell, and cosmetic inconveniences. The patients describe a balance between treatment or no treatment of the skin and a feeling of being caught within the paradox of being damned if they treat the psoriasis, and being damned if they do not [38, 51].

3.2.2. *Psychological Burden of Disease: Change of Self-Concept.*

A number of studies state that patients with psoriasis suffer from an increased level of anxiety and depression [37, 40, 44, 48]. The findings of these cross-sectional studies leave no doubt that the disease results in psychological implications. However, these findings are based on measurements developed chiefly for psychiatric diagnosing, and the study designs are not suited for unearthing causal connections and slight nuances in patient perception. In an Australian study, the patients' descriptions of their experiences of depression and anxiety did not reflect the symptoms as signs of clearly defined psychiatric diagnoses but rather as causally connected with experience of shyness, shamefulness, or social limitation related to the localization and visibility of the disease [53].

Likewise, studies investigating the lived experiences of the patients report that causal connections are complicated when trying to understand the psychological implications of

the disease. The bodily changes caused by the disease and the degree of visibility may result in a changed self-concept. Patients experience that psoriasis has no boundaries in its assault on the physical body and perceive the disease as an enemy attacking the physical self [51]. They describe their bodies as being offensive, unclean, infectious, disgusting, leprous, ugly, unattractive, strange, or different [38]. The attack on the body is experienced as ungraceful, embarrassing, and humiliating, which may result in a feeling of helplessness and powerlessness, especially when not knowing the causes and implications of the disease or their possibilities for getting help or solace. It is concluded that psoriasis may be radically life-changing for the individual's relation to him-/herself and others, thereby resulting in deconstruction and self-fragmentation [51].

This changed self-image has a considerable variety of feelings attached to it. Such feelings may be despair, melancholy, aggression and vulnerability [51], depression and anxiety [41, 45, 53] as well as shamefulness. The highest emotional burden was found in women, but also men were clearly affected by worries about visibility and experience of limitations in relation to social and sexual activities [49, 53].

3.2.3. *Social Burden of Disease: Change of Self-Concept Results in Social Vulnerability.*

Several studies report that the disease considerably influences the social functioning of the patient group [37, 47]. This includes the impact on aspects related to holidays, travelling and making new friends [45], leisure activities such as sports and gymnastics, jobs and school attendance [48] as well as beauty care and cultural events [53].

Self-concept in interaction with reactions in the patient's surroundings and the patient's interpretation of such reactions may lead to social vulnerability. The patients transform their own thoughts and feelings about the look of their skin to other people and suffer from what they think other people think of them [38]. Most patients have the perception that their body no longer supports daily social activities.

Patients describe the fear of being rejected in social contexts as a considerable factor. The fear of being rejected is expressed as a strong wish to hide the disease, to make it nonvisible. Patients talk about respecting the rules of psoriasis in terms of diet and clothing [51]. The patients' struggle to conceal the disease is very time and energy consuming and may often result in considerable restrictions as regards lifestyle and daily activities. In particular, scaling is a nuisance to the patients in daily life, entailing the frequent changing of clothes, increased laundering and, not least, daily cleaning to remove scales from beds, floors, and chairs [38, 49, 53].

A number of studies point out that the disease affects the entire family of the patient. The patients report that, during periods of disease activity, they experience themselves as a burden to their closest family [38]. A recent English study reports that many aspects of patient or family life may be affected. This primarily includes added house work in relation to skin treatment and removal of scales. Other aspects in this context were worry, social limitation due to

embarrassment or the patient's need for help, leisure and holiday limitations as well as stressful relationships to the patient and other people. Finally, the informants pointed out impact on their sexual life [50].

To summarize, the analysis shows that the degree of self-experienced severity and the assessment of the importance of the symptoms are crucial to how patients experience the burden of disease. The analysis shows that the disease may deeply influence daily life for the patients as well as their families/partners. Body perception and self-concept is changed in a way that increases the social vulnerability of the patient group. The fear of being rejected stands out as a considerable factor for planning and activities in daily life. The analysis also shows that in addition to visibility, itch, and skin pain are important in relation to how restrictions are perceived in everyday life.

3.3. Personal Factors. The included studies tend to point in two different directions: (1) one direction stipulating that knowledge of the patients' perception and interpretation of the disease is an important starting point, and (2) another direction emphasizing the knowledge of specific coping strategies of the patient group as a fundamental precondition for being able to help and support patients with psoriasis.

3.3.1. Illness Perception. Several studies state that illness perception is more important for how patients perceive functioning limitations than the extent and severity of the illness *per se*, and also state the existence of an association between illness perception and self-experienced psychological problems [40, 43–45]. Illness perception is constituted by the patient's perception of potential causes for the disease, experienced consequences of the disease, perception of or belief in recovery and control of the disease as well as disease identity.

One study showed that medical treatment of psoriasis affects physical functioning and perception of disease-specific stress but does not affect the patients' worry, perception of the disease, or strategies for managing the disease. Even in cases of considerable improvement of the clinical severity of the disease, the patients' perception of psychological problems and coping strategies, for example, concealing, did not change [44]. This may be connected to the fact that worry and anxiety have been related to cognitive aspects such as illness perception rather than behavioural aspects such as coping strategies [44, 45].

Some studies show that more than 50 per cent of the respondents believe that personal causal connections such as stress may result in psoriasis and subsequent outbreaks [42, 43]. Patients who believe that their disease is emotionally determined experience a considerably larger degree of morbid worry than patients who believe that their disease is determined by physical causes [44]. Stress as an assumed cause is associated with a low level of psychological well-being [43] and reduced knowledge of self-care actions [42]. An English study reported that inequality between the way patients and partners think about the disease may affect the

psychological well-being of both parties as well as the clinical result [45].

3.3.2. Coping Strategies. Studies within nursing [46], psychology [39], and medicine [49] have investigated how patients cope with their disease in daily life. The studies are based on the coping theory developed by Lazarus and Folkmann as it offers a perspective that acknowledges the fact that patients develop coping strategies that interact with their environment. The studies presuppose that it is important to be able to understand the line of action taken by the patient in order to be able to provide support and care for the patient.

One study investigating general ways of coping with chronic medical conditions shows that patients with psoriasis did not apply coping strategies nearly as frequently as patients with chronic fatigue, atrial fibrillation, spinal cord injury, cancer, or myocardial infarction, especially with regard to social support [39]. This is interpreted as an indication that many of the problems experienced by the patients surpass the coping resources of the patient as well as his/her family and social network. Another study shows that having a family, a job or a close friend, being useful or feeling well were factors that facilitated coping and were able to make patients forget that they were suffering from psoriasis [49].

Results from a Norwegian study specifically investigating how individuals cope with severe exacerbation indicate that disease duration, age, and gender are important for the choice of strategy. Women and adolescents use emotional strategies more often than men and elderly people. Disease duration is important for how patients choose to act. The longer a person has lived with the disease, the more often a believe-in-yourself strategy is applied. The opposite is seen in relation to supporting strategies: the shorter the disease duration, the more often a supporting strategy is applied [46]. This indicates that individuals who had lived longer with psoriasis developed personalized knowledge about disease management that made them more independent of support to manage problems from other people. However, the findings from another study indicate that patients, irrespective of gender, choose the strategy that fits into their daily lives. In order to adjust themselves to the disease, the patients transformed the treatment and concealment strategies to everyday routines such as teeth brushing [49].

To summarize, the studies contribute to understanding that cognitive factors, such as illness perception and adequate choice of strategy to manage disease in daily life, have importance for the course of disease. However, patients with psoriasis do not apply coping strategies nearly as frequently as patients with other chronic diseases. The studies indicate that individuals with psoriasis tend to explain their disease based on personal causal connections, with a resulting negative impact on functioning and life quality. The studies also indicate that adolescents are in most need of support to manage their disease, while elderly patients and patients who have suffered from the disease for a long time develop a believe-in-yourself strategy and transform treatment and concealment strategies to everyday routines.

3.4. Synthesis. The analysis indicated a number of high-impact factors that constitute the course of disease and consequently its influence on quality of life, function, and well-being for patients with psoriasis. A synthesis of the findings is shown in the interlevel model in Figure 2.

Figure 2 illustrates that course of disease is constituted through an interaction between various factors, grouped as disease-specific factors, self-experienced burden of disease, and personal (and environmental) factors. For each group, the model lists a selection of factors which, in their own right and in a complex interaction with other factors, influence on how well each patient manages his/her disease in everyday life and is able to achieve better functioning, well-being, and quality of life.

The data comparison demonstrated that visibility is a factor of radical importance to self-perception, social vulnerability, and daily activities in general. It is not the clinical extent of psoriasis, but rather the visibility-associated severity experienced by the patient that determines how severely the burden of disease is felt and which strategies the patient chooses for managing the disease. Furthermore, our analysis suggests a connection between the patient's perception of the disease and how the burden of disease is felt, and that this will influence how the patient chooses to act. The burden of disease is felt more profoundly if the patient's comprehension of what causes the disease is founded in a personal belief of cause and effect. The analysis also suggests that personal relationships with family and partner are significant with regard to social vulnerability and experienced burden of disease, and that quality of life for the patient and his/her partner is influenced by differences in perception of the disease.

The analysis of disease-specific factors suggests that the age at onset time and the time immediately following onset are significant determinants of successful self-management. Early onset influences the burden of disease and, seemingly, personal factors such as illness and body perception, while onset during adulthood does not result in the same degree of emotional strain. The fluctuating nature of the disease is a particular disease-specific factor. The self-experienced severity of the disease and the frequency of fluctuations of the disease seem to influence how well the patients will recover in each period between exacerbations, as well as the patient's self-perception and psychological problems.

4. Discussion and Conclusion

The findings from this integrative review of factors that may impact patients' needs of structured patient education reflect complexity, both in terms of the impact of the disease on the patients' health and quality of life and the specific cultural knowledge of this patient group. The model does not provide any answers as to how learning processes should be organised but contributes to the development of understanding and presentation of health problems in general in this patient group. Not least patients for whom it represents an excess burden, which in fact is the product of the first step in a needs assessment [29]. For this patient group in general,

the most important lesson to be learned from this review is that patient needs must be understood in a complex interaction between self-experienced burden of disease and its visibility, personal conditions such as illness perception, and the patient's age at onset time. These factors appear to be of importance when considering the second phase of a needs assessment, where the connection between the needs and the programme outcomes is established [29], and within nursing, it is necessary to discuss the most appropriate methods and strategies to address the factors.

The experiences of being marked by the visibility of the disease was a finding we had anticipated, given that one in four patients experience significant psychological distress, and a perception of stigmatisation has been reported to be one of the most significant factors related to disability and quality of life [56]. However, the research on stigmatisation in this area has tended to focus on associations between various personal variables such as depression, age, gender and age of onset and to a lesser degree on the social processes reflected in our data. The findings indicate that an overly narrow focus on psychological implications may be problematic because it will always be attached to the individual. It has been discussed that if stigma is viewed as a personal property instead of a label attached by other people, this may have a decisive effect on where the responsibility is placed and, consequently, which interventions are applied [57]. This schism between, on the one hand, health professionals focusing on easing the patients' emotional reactions to their disease and, on the other hand, patients focusing on letting their experiences be expressed as routine actions with the purpose of hiding their disease seems to surface the tension that exists between what the health care system is offering and what patients think they need. Patient education interventions have often been organised in accordance with the needs of the clinician and the system taking priority in the delivery of patient care. In models like this, the professional is at the centre of the system, and the patient is expected to comply with the instructions given by the health care professional. If our findings are seen in a self-management perspective, they indicate that visibility can, with advantage, be understood in relation to how patients act on it as part of their struggle to create order and control in daily life.

In agreement with previous research within other chronic conditions [58] patients' causal beliefs of the illness and its consequences appear to be of greater importance for the patient group's health-related quality of life than the factual clinical severity of the illness. Worry and anxiety related to illness perception may limit the patients' choice of alternative points of view on themselves, their world, and their future. Nevertheless, illness perception must be emphasised as an important factor in relation to psoriasis patients, as in two of the studies 60 and 54 per cent of the patients, respectively, stated person-specific factors like stress as being the cause of their disease [42, 43, 59]. This is confirmed by a review [56] showing that 37–88 per cent of the included patients stated stress as a disease cause. Recent stress research confirms that a majority of patients believe this to be true, but clearly states that stress cannot be established as a triggering factor in relation to psoriasis [56].

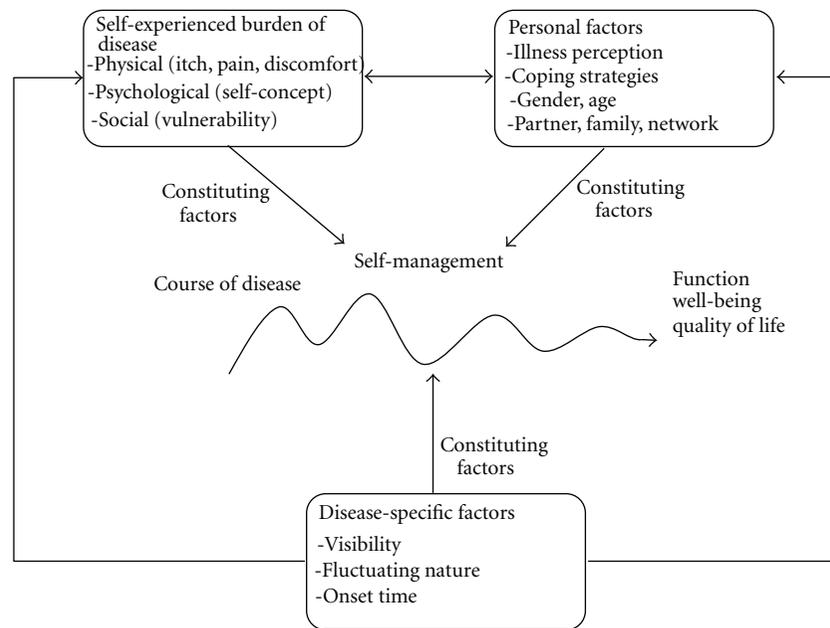


FIGURE 2: High-impact factors for patient self-management of psoriasis in daily life.

This discrepancy could be due to the fact that the disease has not, until recently, been recognised as an autoimmune-mediated disease. For many years, it was a prevailing hypothesis that patients with psoriasis had a certain style of personality [40, 56]. From this outset, health professionals have sought explanations for the disease in the patients' personal factors and stressful life events, and it has been suggested that health professionals may have contributed to creating this understanding [43]. For psoriasis patients, this understanding may have resulted in being particularly vulnerable to topics such as psychological condition and lifestyle, given a basic perception that they themselves are the reason for the onset and flare-ups of their disease. It is already known that patients with a disease of unknown causality are vulnerable to communication related to their psychological condition [28]. Historically, patients may have adapted the perception that no doubt has unconsciously been signalled by the health professions. Thus, the patients' illness perception is an important factor that should be taken into account when appraising the patient group's needs for patient education. Here lies a commitment to communicate the latest findings on disease causality if such knowledge prevents psychological difficulties.

The Danish Center for Health Technology Assessment [19] found that people with chronic diseases need disease-specific knowledge and skills. Still, what is supposed to happen within the communication to steer the patients' course of disease is not at all well-known, and the HTA does not provide any comprehensive overviews of these needs. It is pointed out that the focus should be on the patients instead of the health care professionals' assumptions about the needs and the preferences of the patients. This means that the nursing discipline must critically discuss the customary

way of defining clinical outcomes and the outcomes that are important for patients to live well with their disease. Thorne warns against the evaluation of interventions in terms of available indicators of treatment compliance and lifestyle control [60] and challenges nursing to adopt the perspective of expert patients; that there is no single way to live well with a chronic condition; that the learning process is complex and stepwise; and that the role of nursing science must be contextualised within an understanding of the living that is taking place [61].

There is emerging evidence that interventions that specifically aim to increase the patients' level of self-efficacy are more likely to produce positive outcomes in terms of behaviour change and health outcome. De Silva [62] for example, has reported that people with chronic conditions benefit from different outcomes like improvement of knowledge, technical skills, self-efficacy, and behaviour change. It may however be questioned whether these existing outcome measures really capture the benefits that are most important to the participants in the programmes. If this is not the case, many important factors can get left out when the impact of a programme is evaluated.

Our findings indicate that the outcomes must reflect the factors that may be important for the individual patient, both in spontaneous patient education and in planning for a more structured process. Outcomes must reflect how far the patient is in his or her course of the disease, how the burden of disease is experienced, how the body and illness is experienced, and the best ways for the patient to manage the disease. It seems that varied approaches are needed and that researchers in nursing science must build relationships with the patients and engage them in the research to map the outcomes which really benefit their lives.

According to the theoretical concept behind needs assessment and health promotion intervention, “nothing is as useful as good theory” ([63] page 8). This means that when developing patient education programmes, the choice of a (multi-)theoretical framework contributes to a coherent intervention development addressing the content, the pedagogical methods, the organisational structures, the competency development of the health care professionals, and the development of outcome measures. However, based on the findings of this review it could be important to question whether these theoretically defined outcomes really meet actual patient needs.

Kennedy and Phillips argue for broader and more patient-centered measures to capture the social impact of patient education programmes [64]. They have shown that participating in a well-defined and evidence-based programmed as the Expert Patient Program [65] improved the participants’ confidence, knowledge, and skills as a part of the programme curriculum, for example, improved diet, meeting new people, ability to control emotions, increased self-awareness, and increased self-worth. But these outcomes were not those valued most by the participants [64]. In focus group discussions with participants, the ancillary (not health-related) impact of the programme was mapped, and a general “theory of change” for this particular patient group was developed and tested. It seems that an increase in confidence leads to further outcomes such as decreased anxiety, better sleep, the ability to try new things, and increased motivation. Thus this method permits the mapping of variety of outcomes experienced by different participants, for example, improved relationships with family and friends, participating in volunteering initiatives, further education, or job-related outcomes.

Our findings indicate that when evaluating the patient group’s general needs for patient education, the health care professionals must pay more attention to the various life phases where psoriasis sets in. This issue has not yet been focused on in a scientific context, and onset time is not an articulated theme in the included studies. The findings can be seen in the light of recent knowledge that the disease sets in either at an early age or relatively late in life. More than half of the patients experience onset before they reach 20, in most cases with the first symptoms appearing before the age of 16. For the majority of the rest of the patient group, onset does not occur until the age of 50 to 60. The group with early onset is characterised by a higher severity of the disease, while the group with late onset is characterised by lower illness severity [2, 66]. Our data material is characterised by no inclusion of very young people in any of the studies. The average age for the included patients was between 40 and 52 years. Several studies included middle-aged patients with early onset, a fact that stands very clear in their memory. In the studies, the patients recounted in retrospect their fear of never being able to get a partner, a job, or a close friend, and that nobody would ever come to like them [49, 67]. These stories illustrate that onset during adolescence was a great strain on them, and described as devastating. Our review indicates that patients with onset during adolescence had by far more difficulties with managing their daily life than patients

with adult onset, especially with regard to psychological difficulties related to body and self-perception. One study found that psychological difficulties were particularly distinct in individuals who had experienced teasing or bullying as children or adolescents [53]. Research in young people with psoriasis is indeed limited, but a theoretical study indicates onset time to be a decisive factor for development of psychological difficulties [68]. In accordance with our findings, this study describes the onset of the disease in late childhood being experienced as a stranger and therefore a frightening experience. Patients in this developmental phase have a strong wish to understand what is happening to them. The study also points out that patients who do not get sufficient support to socialise with their contemporaries often tend to develop emotional problems and academic difficulties as adults. Findings from an online focus group survey [69] including young people between 11 and 18 showed that the young people struggle to make the disease fit into their lives. It is a struggle between “it” and “me”, and the struggle is about controlling “it” and minimising its influence on their appearance and social functioning. Through the research process when articulating their experiences, the young people became aware that they were not alone in their struggle and were spontaneously practising *peer support* to help each other. The study argues that the resources achieved during adolescence are significant for the ensuing adult life phase. It seems likely that the potentially negative long-term effect of psoriasis may be reduced by participating in network groups during adolescence.

It appears that onset time is a high-impact factor that must be integrated in the planning of structured patient education programmes, taking into account that onset time is related to two very different age groups with different life phase challenges. In particular, it appears that we must increase our focus on the problems and the vulnerability related to having a visible disease such as psoriasis during childhood and adolescence and acknowledge the need for a preventive intervention at an early stage.

Overall, our findings indicate that further research is needed on the needs of patient education programmes. The research would benefit from the involvement of especially the young people in particular to explore their specific needs including specific and various outcomes relevant to their everyday life. When participants are involved in the designing process of patient education, they prioritise the educational content very differently from their teachers. Booker et al. [70] argue for development of educational interventions in cooperation with the patients using focus group discussions to articulate problems and outcomes. This is important both in relation to children and parents, as children need to understand what is happening to them, and in relation to adolescents during the critical period of developing their identity when they not only need family support but, to a greater extent, compare themselves with their contemporaries.

4.1. Study Limitations. This review has some limitations due to the complex method. On the one hand, the preliminary

search of this review indicated limited research on nursing and nursing intervention within this patient group. On the other hand, the search revealed a widespread research reporting on the impact on quality of life, function, and well-being. The establishment of the theoretical scaffolding around “needs” ensured well-defined key words and improved the sensitivity of the search. This resulted in an extensive data material that enriched the understanding of patients’ needs but challenged the selections and analytical process. Ideally, all relevant literature should be included in the review, and more studies might have been included to contribute to data saturation. However, a high degree of retrieval throughout the search process indicates that the review constitutes a representative picture of the available scientific knowledge on the phenomenon [32].

Given that the review is based on original studies from different disciplines and methodologies, there might be some limitations with regard to the data extraction. Although we have sought to be compliant with the research tradition, methods, concepts, and theories of the various disciplines, this complexity may have constituted a risk of misinterpreting the quality and the findings of some studies. However, we have put the interpretation of the existing knowledge into the context of current health care and into a theoretical understanding of the patients’ perspective on self-management. This may contribute to the cumulative knowledge in nursing science and practice [71].

The review may also be confined due to the complexity of the data evaluation. Several of the primary sources contained weaknesses with regard to the selected quality criteria, but overall the quality was high. The studies that were valued less good were to a lesser extent used in the analysis, for example, when the statement of the problem was not quite clear or the questionnaire was only partially validated.

It can be discussed whether our findings concerning the young people are transferable to present time, considering the relatively high average age and illness duration of the participants as the participants’ experiences in most cases were formed in contexts more than a generation ago. It is questionable whether psychosocial difficulties experienced by the participants during adolescence would be similar today. We have found the difficulties to be transferable to present time, as body experience and self-representation during adolescence is more important than ever in Western countries.

The integrative review method is not different from other systematic review methods with regard to the fact that bias and errors may occur at any stage of the review process, and that attempting to eliminate all biases would be naïve. What is characteristic for this particular method is its ability to comprehend knowledge about a phenomenon in various disciplines and methodologies and the use of inductive analysis methods. This means that its foundation is not collection and comparison of evidence but an interpretation of existing knowledge. The aim of this analytic form extends beyond taking things apart and putting them back together again [35]. We present an interpretation that has the potential to contribute to present varied perspectives of the patients’ needs and is thereby important to both nursing practice and

nursing science. We have tried to ensure the validity and transferability of the interpretation by presenting the rather comprehensive (Table 2) that shows the data extraction of key data reported as thoroughly as possible, using the original language and expressions of the studies reviewed.

4.2. Conclusion. The aim of this integrative review has been to identify and describe patient needs for education to support self-management in daily life with psoriasis. We have identified a range of high-impact factors associated with the disease and its course that substantially influence the quality of life, functioning, and well-being of the patient group. These factors constitute, in mutual complex interaction, the course of disease and are significant with regard to how well the patient is able to manage his/her disease in everyday life. The factors are grouped into three clusters consisting of disease-specific factors, personal factors, and self-experienced burden of disease. We conclude that some of these factors may be particularly important to take into account when developing education programmes for this specific patient group. Among these factors are the patients’ illness perception, how the visibility of the disease influences the psychological and social burden of the disease, and, not least, the particular importance of onset time, especially for the young patient group.

The study offers a profound understanding of what may be important to patients participating in self-management education, and the interlevel model offers a contribution to nursing practice to encourage nurses to involve patients in the development of new interventions.

Authors’ Contribution

G. S. Rasmussen was involved in all phases of the study and of writing the paper. K. Lomborg was involved in deciding study design, drafting of paper, critical revision of important intellectual content, and supervision. H. T. Maindal was involved in critical revision of the paper.

Conflict of Interests

The authors declare that they no conflict of interests.

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Research Article

Design and Development of a Telerehabilitation Self-Management Program for Persons with Chronic Lower Limb Swelling and Mobility Limitations: Preliminary Evidence

Becky L. Faett,¹ Mary Jo Geyer,¹ Leslie A. Hoffman,² and David M. Brienza¹

¹ Department of Rehabilitation Science and Technology, School of Health and Rehabilitation Sciences, University of Pittsburgh, Suite 401, 6425 Penn Avenue, Pittsburgh, PA 15206, USA

² Department of Acute and Tertiary Care, School of Nursing, University of Pittsburgh, 336 Victoria Building, 3500 Victoria Street, Pittsburgh, PA 15261, USA

Correspondence should be addressed to Becky L. Faett, faettb@pitt.edu

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This paper describes design and development of a self-management program, delivered by telerehabilitation (TR), to address the problem of chronic lower limb swelling in persons with limited mobility. The 18.6 million persons with limited mobility in the USA are at increased risk for chronic lower limb swelling and related secondary complications, including cellulitis and skin ulcers. Over time, chronic swelling often progresses to lymphedema, an incurable condition requiring lifelong care. Without successful self-management, lymphedema and its related complications inevitably worsen. Access and adherence to appropriate treatment are challenging for persons with limited mobility. Program development involved a structured process to establish content validity (videos and manuals), readability, suitability, and selection of a TR platform to deliver the educational program. Our goal was to develop a program that would engage patients in self-management skills. The TR software platform chosen, Versatile and Integrated System for Telerehabilitation (VISYTER) was designed to facilitate face-to-face delivery of an interactive home-based self-management program via the internet in real time. Results demonstrated validity of the educational program and ease of use with TR. Future plans are to evaluate ability of this approach to promote self-management skills, home monitoring, and improved management of persons with lymphedema and limited mobility.

1. Introduction

Lymphedema, an incurable health condition, occurs when an impairment of the lymphatic system results in a lymphatic load that is greater than lymphatic transport capacity. The consequence is accumulation of protein-rich fluid in the interstitial space [1, 2]. Over time, this high concentration of protein stimulates an inflammatory response leading to fibrotic changes in subcutaneous tissue and hypertrophy of adipose tissue [3]. Protein-rich lymph provides a fertile medium for bacterial growth [3]. If untreated, lymphedema can progress, causing continued proliferation of fibrotic tissue, an increase in size of the affected limb, an increased risk for wounds [4, 5], life-threatening infections, loss of functional ability [6], and decreased quality of life [7, 8]. Lymphedema is classified as primary or secondary. Primary

lymphedema is congenital and rare [9], while secondary or “acquired” lymphedema is common. Causes of secondary lymphedema include surgery for carcinoma that involves damage or dissection of lymph nodes, radiation therapy, trauma to lymph nodes or vessels, chronic infection, chronic venous insufficiency, tumors that obstruct the lymphatic flow, and/or a combination of the these conditions [6, 10, 11].

People with mobility limitations are at high risk for chronic lower extremity swelling. The return of fluids via the venous and lymphatic system is facilitated by muscle contractions of the legs. This physiologic mechanism is hindered or absent in people who use wheelchairs for mobility. Sitting for long periods of time applies pressure to capillaries and lymphatic vessels that also impedes flow. Poor body trunk alignment negatively affects the normal respiratory pump

for the lymphatic system and further reduces lymphatic flow [12].

Complete decongestive therapy (CDT) is the gold standard treatment for management of chronic lymphedema [13–16]. The goal of CDT is to reduce swelling and tissue fibrosis, improve functional ability, prevent infections [13, 16], and stop the progression of the disease. CDT is provided in two phases. Phase I is completed within the clinical setting by a certified lymphedema therapist. It consists of manual lymphatic drainage (specialized massage) to facilitate central lymph flow and promote movement of the lymph out of the effective limb, multilayer short stretch compression bandaging of the extremity, diaphragmatic breathing and exercise to further enhance lymph flow, a low salt diet, and meticulous skin care [2, 9, 10, 13, 16–18]. Phase II involves the continued maintenance of these labor-intensive activities for life by the patient. Nonadherence with home maintenance has been shown to minimize the benefits of CDT [19].

Access to therapists specializing in CDT is challenging. First, there are few certified lymphedema therapists and those available are primarily located in urban areas. Patients with limited mobility may have difficulty obtaining transportation that accommodates their needs. Public transportation is often difficult to access or unavailable, especially in rural areas [20]. Most wheelchair users (82%) report that public transportation is difficult to access [21]. Costs are another concern. Most third-party payers limit the number of paid visits per year and require copayments. Only 43% of people with disabilities earn wages for employment and 17% report they have no health care insurance [22]. In order to address barriers faced by people with limited mobility in achieving access to treatment and management of chronic swelling, alternative treatment strategies need to be identified. One such alternative is the use of telerehabilitation to provide a remote self-management program.

Telerehabilitation (TR) has been defined as “the application of telecommunications, remote sensing and operation, and computing technologies to the delivery of medical rehabilitation services at a distance” [23, p. 115]. Considered a subspecialty of telehealth, TR can be provided using a variety of modes. These include “face-to-face” videoconferencing, telehomecare to coordinate in-home therapy and patient support, in-home patient telemonitoring, and teletherapy for exercise supervision by a remote therapist [24]. Selection of the most appropriate mode requires consideration of the needs of the patient population, equipment capabilities, available bandwidth, and clinician skills.

TR has the potential to improve access to specialty care and provide services within the home environment, thereby meeting needs expressed by those with mobility limitations. Limitation in mobility impacts an estimated 18.6 million people in the USA [20]. Studies have shown TR to be a valid and reliable modality for assessment of patients with mobility limitations. TR applications range from determining appropriate wheelchair seating to management of skin ulcers to providing complex treatment modalities [25–28]. TR has been shown to increase functional mobility in patients after stroke, [29, 30] after knee arthroplasty, [31] with cerebral palsy, [32] and with multiple sclerosis [33].

Telecommunication has also been shown to be effective in providing remote self-management programs for chronic conditions, resulting in improved health care outcomes [34–36]. Patients have reported high levels of satisfaction with health care delivered by TR [31, 37, 38].

Self-management is defined as “an individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic disease” [39, p.563]. Lorig and Holman [40] describe five core skills for self-management of chronic conditions. The first is problem solving, that is, the ability to identify both problems and possible solutions. Decision-making is the second skill, that is, having the knowledge to make appropriate decisions in response to one’s current status. The third skill is developing the ability to find and utilize appropriate resources, that is, the Internet, library, community resources, and support groups. The fourth skill is the ability to develop a true partnership with health care professionals. Patients must work in conjunction with health care providers to appropriately evaluate and monitor their responses to therapy, to know when to ask for help, and determine when to modify their care in order to meet their needs. The fifth and final skill is the ability to implement and evaluate a plan of self-care. Patients need to learn how to develop their own short-term measurable goals, evaluate the level of their success in meeting those goals, and determine when they need to modify or set new goals to achieve optimum self-management of their chronic condition [40].

Self-management theory is grounded in the expectation that increasing patients’ belief in their ability to manage their illness will result in positive change and better health care outcomes [41]. This belief, known as perceived self-efficacy, is defined as “the confidence a person feels about performing a particular activity, including confidence in overcoming the barriers to performing that behavior” [42, p. 173]. According to Albert Bandura’s Social Cognitive Theory of Self-Regulation, a person’s perception of their self-efficacy will impact their decisions in life, their goals, and how they respond to adversity. The more competent a person believes themselves to be, the higher the goals they will establish and the more determined they will be to overcome adversity in meeting those goals [43]. Research has shown a positive correlation between self-efficacy and health care outcomes [44, 45], and high self-efficacy is a predictor of the success of behavioral interventions [46, 47]. Self-management programs have been shown to increase self-efficacy, improve health behaviors [45], improve healthcare outcomes [45, 48, 49], and decrease health care utilization [50, 51]. Therefore, the intent of “Telerehabilitation: Empowering You to Manage and Prevent Swelling” (TR-PUMPS) was to deliver a standardized educational program for self-management of chronic lower limb swelling, monitor health status, and assess the ability to perform required skills via real-time teleconferencing in a population of persons with limited mobility.

In order to address barriers faced by people with limited mobility, an alternative treatment strategy was proposed and designed for remote delivery via TR. The TR-PUMPS educational program was developed as a critical component

TABLE 1: 10 Steps to healthier feet and legs.

Step	Goal
1	Understand basic pathophysiology of the vascular and lymphatic system, including warning signs of vascular, lymphatic, and neurological damage.
2	Demonstrate proper limb hygiene, for example, washing and drying technique and nail care.
3	Describe proper use of moisturizers and appropriate application.
4	Relate steps during skin inspection for changes such as redness, wounds, skins cracks, blisters, and excessive dryness and increased hardness.
5	Describe proper care for minor skin wounds.
6	Describe how to select appropriate footwear and clothing.
7	Demonstrate strategies to prevent/minimize swelling, including leg elevation, avoidance of excessive heat, and proper diet.
8	Demonstrate appropriate deep breathing and decongestive exercises.
9	Demonstrate appropriate application and care of an advanced pneumatic compression device and compression garments.
10	State signs and symptoms and appropriate action when complications develop, for example, deep venous thrombosis, pulmonary emboli, pulmonary congestion, edema, and/or infection.

of a clinical trial to evaluate the effects of a TR for immobile individuals with chronic edema/lymphedema of the lower limbs (NIDRR Grant no. H133E090002). In the clinical trial, TR was chosen as a novel delivery method for a modified lymphedema treatment protocol including advanced pneumatic compression. A review of the literature revealed no previous studies of self-management strategies for swelling in this high-risk population with limited mobility.

2. Methods

2.1. Content Development. Based on current best practice for treatment of chronic edema/lymphedema, a draft version of the educational protocol was developed with input from three certified lymphedema therapists. Based on current best practice for treatment of chronic edema/lymphedema, the script identified 10 learning goals central to self-management for chronic edema of the lower extremities (see Table 1). The next challenge was to develop evidence-based content for each of these steps at a suitable reading level.

2.2. Evaluating Readability. Studies have shown that patient educational materials often have a higher readability level than recommended by the American Medical Association (5th to 6th grade) [52–56]. Patient comprehension had been shown to increase when presented at a 5th-grade level [57]. Thus, after developing draft content for the educational program, the next step involved testing readability level. Formulas frequently used to evaluate the grade level of a written text include the *Flesh Reading Ease Scale*, *Flesch-Kincaid*, *Gunning Fog Index*, *SMOG Formula*, and *Fry Formula* [58]. These formulas use the number of polysyllable words and sentence length to calculate readability [58]. Therefore, all have a common limitation—they assume that more syllables increase reading difficulty. However, in reality, multisyllable words may be easier to comprehend.

Electronic software packages offer another option. Mailoux, et al. [59] performed a study to compare results

obtained when using readability formulas with those obtained when using four software packages: *Corporate Voice*, *Grammatix IV*, *Microsoft Word for Windows*, and *RightWriter*. Results showed significant differences between the several formulas, but no significant difference in the means of overall grade levels produced by the *Corporate Voice*, *Grammatix IV*, and *RightWriter* software programs.

Because of the variability in readability level that could result from these various tools, we followed the recommendations to use several formulas and software programs [58, 59]. The computer software *RightWriter* (Elite Minds, Inc.) was used to evaluate the readability level of the educational scripts. *RightWriter* employs two readability formulas, the *Flesch-Kincaid* and the *Gunning Fog Index* and also evaluates for active versus passive voice and jargon. A second evaluation was completed using the *Microsoft Word for Windows* readability program.

2.3. Video Development. Next, the final revised scripts were used to develop videos for the TR protocol. A video was developed for each of the 10 steps with the length of each video ranging from 1.5 to 11 minutes. The videos illustrated specific skills such as decongestive exercises and donning and doffing of compression garments. Each video was subdivided into individual skills or tasks to permit ease of locating and viewing during TR sessions. To establish content validity, the videos were viewed by eight additional board-certified lymphedema therapists who anonymously ranked each video on accuracy and completeness of the information as well as the clarity of the presentation. A 5-point Likert scale (5 = strongly agree to 1 = strongly disagree) was used to determine the therapists' level of agreement with descriptive statements about the content of each video (See Table 2).

When the TR program is operational, the videos will be available electronically via a portal that participants can access from their home computer. The videos will also be used during teleconferencing to teach the 10-step program and to reinforce teaching during review sessions.

TABLE 2: Excerpts from the tool used to evaluate video content.

Please respond to the following questions by placing a number in the box that matches your level of agreement	Strongly agree 5	Agree 4	Neither agree nor disagree 3	Disagree 2	Strongly disagree 1
Step 1: Know about your feet and legs					
(1) The basic anatomy and physiology are clearly explained					
(2) Anatomy and physiology provide rationale for interventions at basic level					
(3) The warning signs of poor circulation are accurate and complete					
(4) The warning signs for chronic swelling are accurate and complete					
(5) The warning signs for neuropathy are accurate and complete					
(6) Comorbidity is explained as well as the need for differential diagnosis					
Step 2: Wash and dry daily					
(1) Rationale for daily washing is clearly explained					
(2) Preparation for washing is accurate and complete					
(3) Washing technique is accurate and complete					
(4) Criteria for helper assistance and performance requirements are clearly explained					
(5) Preparation for drying is accurate and complete					
(6) Drying techniques are accurate and complete					
(7) Precautions are accurate and complete					
(8) Instructions to wash and dry both affected and unaffected foot and leg in the same manner are clear					

2.4. Educational Booklet. To supplement the videos, an educational booklet was developed using the same 10-step approach. Illustrations and still frames from the videos were used to augment the script. The booklet was evaluated for suitability utilizing the Suitability Assessment of Materials (SAM) [60, 61]. Suitability refers to the ability of the material to be understood and acceptable by the targeted patient population [60]. The SAM rates educational material using 6 criteria: (1) content, (2) literacy demand, (3) graphics, (4) layout and typography, (5) learning stimulation, and (6) motivation and cultural appropriateness. These criteria are comprised of 22 factors. Each factor is scored superior (2 points), adequate (1 point), or not suitable (0 point). Scores are totaled for an overall rating expressed as a percentage (actual score divided by total possible score). Educational material with a score of 0%–39% is given a rating of “inadequate suitability”, 40%–69% is given a rating of “adequate suitability”, and 70% and above is rated as “superior suitability” [60, 61].

2.5. Implementing Telerehabilitation Protocol. The *Versatile and Integrated System for Telerehabilitation* (VISYTER) software platform was chosen for use in this self-management program and tailored to specific educational needs. VISYTER was developed at the University of Pittsburgh, School of Health and Rehabilitation Sciences, Department of Rehabilitation Science and Technology with funding from the National Institute for Disability and Rehabilitation Research via the Rehabilitation Engineering and Research Center on Telerehabilitation. It was selected because of its demonstrated effectiveness and flexibility in conducting remote face-to-face evaluations [25]. VISYTER is a secure system that provides users the ability for real-time teleconferencing with multiple remote camera control, sharing of educational videos through Microsoft Windows Media Player, and the ability to archive teleconferencing sessions and still images [62]. Minimum computer requirements include “Pentium Dual Core processor 2 GHz with 2 GB of RAM and an NVIDIA GeForce 4 Series graphic card” [63]. VISYTER requires an internet connection with an upstream and downstream speed of approximately 1.5 Mbps for medium quality video.

The use of the VISYTER system was tailored for use in the delivery of educational materials by loading the videos onto the system and performing laboratory testing of all capabilities prior to actual participant use. The first step when used in the home involves downloading the software onto a participant’s home computer. Participants will be provided with a ClearOne CHAT 60 speakerphone. If no built-in web cam is available, a Logitech HD C910 web cam will be used for face-to-face videoconferencing. A second camera, the Logitech Orbit AF, can be connected to the participant’s computer for use in skin and skill assessments. The Logitech Orbit AF will provide clinicians with the ability to remotely control the camera’s movement and zoom capabilities. The clinician at the remote computer site will use a Logitech HD C910 web cam and a Logitech USB headset. A personal user ID and password will be assigned to each participant to enable them to log on to VISYTER.

Each participant will also be assigned his or her own virtual clinic room. VISYTER’s virtual clinic rooms are housed on the server and can only be accessed by authorized users. An assigned room administrator will determine the user’s access and specific access capabilities which might vary depending upon their role [62]. Training will be provided to participants on how to use the VISYTER software to connect to the remote clinician (see Figure 1).

To implement the self-management program, the participant and clinician will connect to a VISYTER virtual clinic room via the portal in what is termed the “Lymphedema Venue” for each teleconferencing session. During the initial session, participants will be asked to identify five specific occupational performance goals. A plan of action will be developed in a collaborative effort between the participant and clinician. The participant’s comprehension on lymphedema self-management will be evaluated, and any barriers that could negatively affect the participant’s ability to perform the 10 steps of the self-management program will be identified (See Figure 2).

Real-time interactive education and evaluation sessions will occur a minimum of once per week for six weeks. The frequency of sessions will be determined by mutual agreement based on a joint review of the participant’s current knowledge of their condition and self-management skills. Educational videos will be used to train the participants using the media sharing capabilities of the VISYTER software. Comprehension and retention of the educational material will be evaluated through participant verbal recall and performance of return demonstrations. All electronic communications will be encrypted to maintain privacy. TR interventions can be recorded and saved in an archived data base within the server.

The final step involved uploading the videos to the Lymphedema venue and the testing of the VISYTER software’s performance in the delivery of the educational protocol within a laboratory setting. To conduct this evaluation, we transmitted from our virtual clinic workstation to distant rooms to test transmission in a simulated home setting. Bandwidth was tested to determine the speed necessary for providing the self-management program.

3. Results

3.1. Readability. When evaluated for readability utilizing the computer software *RightWriter* (Elite Minds, Inc.), *Flesh Kincaid* results indicated a readability level of a 4.01 grade level. The *Gunning Fog Index* resulted in readability level of a 5.61-grade level. The average of these two formulas resulted in an overall readability level below the 5th-grade level. A second evaluation using the *Microsoft Word for Windows* readability program resulted in a *Flesh Kincaid* readability level at a 3.4-grade level.

3.2. Content Validity. When content validity of the educational videos was determined by eight experienced, board-certified lymphedema therapists, the mean score was 4.5 ± 0.35 with a range of 4.1–4.9 (see Table 3).

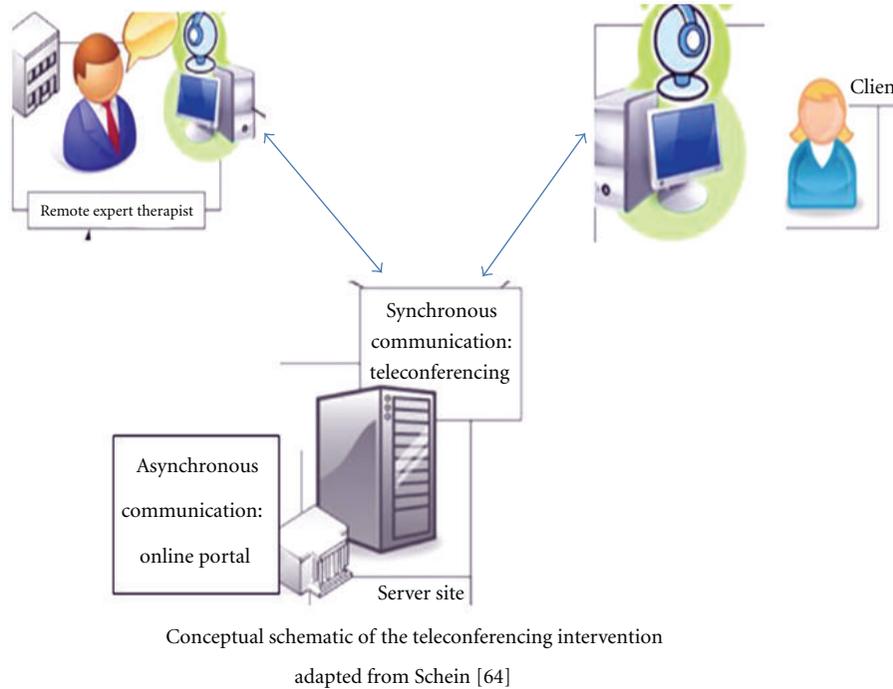


FIGURE 1: Conceptual schematic of teleconferencing intervention adapted with permission from Schein [64].

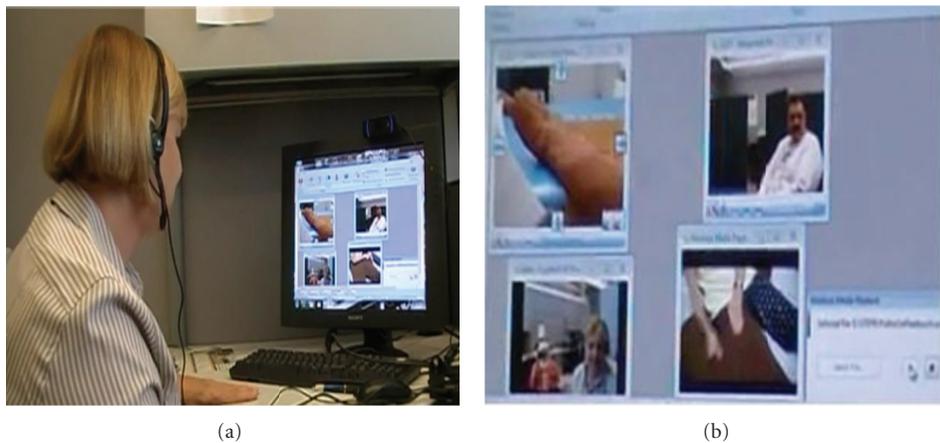


FIGURE 2: Remote clinician (a). Simulated telerehabilitation session (b). The right panel, top left, shows an image from video camera with remote control capabilities used for assessment; the right panel, top right, shows an image of a face-to-face intervention; the right panel, bottom left, shows an image of what the participant observes from their camera; the right panel, bottom right, shows educational video used for client education.

3.3. Suitability. The supplemental educational booklet, developed using the same script as the videos, was evaluated for suitability utilizing the Suitability Assessment of Materials [61]. A score of 77% was achieved, resulting in a superior rating.

3.4. TR Program Function. The video file format, *QuickTime Format*, used for the videos was not compatible with the VISYTER software platform. The video file format was therefore changed to the *Windows Media Video Format* to allow sharing of the videos during video conferencing. The

ability for participants to access and download videos from the lymphedema portal was verified.

Transmission speed was determined using two cameras plus audio upload on the participants' side and one camera and media sharing and audio download on the clinician's side. It was determined that a medium-quality video was sufficient for the face to-face interaction. However, high video quality was required for the remote camera for visualization during skin assessments. Results of the laboratory testing determined that speeds of 1220 kbps upload and download were the minimum requirements and the speed

TABLE 3: Rating of lymphedema therapists for video content validity. Rating scale was 5: strongly agree to 1: strongly disagree.

Video	1	2	3	4	5	6	7	8	9	10
Mean	4	4.19	4.8	4.5	4.6	4.55	4.48	4.38	4.34	4.9
Mode	4	4	5	4	4	4	4	4	4	4

of 1620+ kbps upload and download provided optimal teleconferencing audio and visual quality.

4. Discussion

The study's researchers' collaborative efforts resulted in the development of a comprehensive self-management program for patients with chronic lymphedema with appropriate readability and suitability scores that was highly rated by external evaluators in regard to its content validity and selection of a software platform with the potential to provide in-home teleconferencing and assessment capabilities.

Healthy People 2010 defines health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" [65]. The 2003 National Assessment of Adult Literacy (NAAL) survey results showed that only 12% of adults in the USA had proficient health literacy [66]. Inadequate health literacy has been associated with a decreased ability to communicate with health care providers [67], decreased knowledge and self-management skills of chronic conditions [68–70], and poorer health care outcomes [71, 72]. In order to address health literacy disparity, health care professionals need to provide education materials that are appropriate for all health literacy levels. Adult readers of all reading levels prefer and learn better with easy-to-read instructions [61]. Self-management programs that are tailored for patients with inadequate health literacy have been shown to overcome learning barriers, increase self-management skills, and reduce the rate of hospitalization and death [49, 73].

A variety of readability software and formulas are available to evaluate readability levels. A concern, as shown in our study, is that different readability formulas can produce discrepancies in grade-level results with scores deviating as high as 41% [59]. Consequently, we advise using several formulas and averaging the results [58, 59]. Our study produced results using several tools that ranged from 3.4 to 5.61, supporting findings of prior studies [58, 59]. To obtain additional information on readability formulas, the website for the *plain and simple* project from the Iowa Department of Public Health is recommended and may be accessed at <http://www.idph.state.ia.us/PlainAndSimple/Readability.aspx>. This website provides information on commonly used readability formulas and access to readability calculating software at no cost.

Readability level is not the only factor that determines the effectiveness of written material when attempting to address health literacy disparity [55, 61, 74]. Suitability of the material for the targeted population also needs to be evaluated. To perform this assessment, we chose the Suitability Assessment of Materials (SAM) developed by Cecilia

Doak and Jane Root. SAM was validated in a study enrolling 172 health care professionals from various countries [56] and has been widely used to evaluate educational material related to a variety of diseases [56, 75–78]. Additional information on SAM may be found in *Teaching Patients with Low Literacy Skills (2nd Ed)* by Doak et al. [61]. This text may be downloaded at no cost from <http://www.hsph.harvard.edu/healthliteracy/resources/>.

With advances in information technology, telecommunications offers health care providers the opportunity to utilize new approaches to health care delivery. The current health care delivery system is focused on acute care. With the aging population and the increase in chronic conditions, this health care delivery system is not meeting the public's needs. Chronic conditions result in seven out of ten deaths in the USA. As of 2005, 133 million people in the USA suffered from at least one chronic condition. This number is projected to increase to 157 million people by 2020 [79]. The increase in the prevalence of chronic conditions is contributed to the increasing age of the population and an increase in risk factors such as obesity which predispose chronic illness [79]. The occurrence of people having multiple chronic conditions increases with age, with 25% of Medicare recipients having at least four chronic conditions [41]. This rise in chronic conditions is creating an increased financial burden on the health care industry with costs associated with the management of these chronic diseases accounting for 75% of all health care costs [80]. A redesigning of the current health care system to provide a continuum of health care to people with chronic conditions is necessary [81]. Recommendations for redesign of health care delivery systems by the Institute of Medicine (IOM) include that patients be informed decision makers in their health care, health care should be customized according to patients' needs and values, and health care should be readily available and provided not just by face-to-face visits but also by internet or telephone [81]. In 2007, only 13.6% of people reported using the internet as a source of communication with their health care provider [82]. A goal of Healthy People 2020 is to increase this to 15.7% [82]. The utilization of TR to provide self-management programs for chronic conditions can be a potential resource in facilitating a continuum of care that is patient-centered and focused on providing patients with the knowledge and skills to enable them be actively involved in the management of their chronic conditions.

5. Conclusion

The evidence-based educational materials developed as part of the self-management program for lower limb chronic swelling/lymphedema in persons with limited mobility were found to be valid, accurate, and complete with high ratings of

clarity. The readability and suitability ratings indicated that the materials are appropriate for various levels of health literacy in the study population. The self-management program described may be applicable to address other chronic conditions such as diabetes, heart failure, and chronic obstruction pulmonary disease. We believe TR is a viable method of providing a home-based self-management program on lower limb chronic swelling/lymphedema in people with mobility limitations and can decrease the burden associated with lifelong management of this debilitating condition.

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Research Article

Social Processes That Can Facilitate and Sustain Individual Self-Management for People with Chronic Conditions

Elizabeth Kendall,¹ Michele M. Foster,² Carolyn Ehrlich,¹ and Wendy Chaboyer³

¹Centre for National Research on Disability and Rehabilitation Medicine, Griffith Health Institute, Griffith University, Logan Campus, Meadowbrook, QLD 4131, Australia

²School of Social Work & Human Services, The University of Queensland, St. Lucia, QLD 4072, Australia

³NHMRC Centre of Research Excellence in Nursing Interventions for Hospitalised Patients, Research Centre for Clinical and Community Practice Innovation and Griffith Health Institute, Griffith University, Gold Coast Campus, Southport, QLD 4215, Australia

Correspondence should be addressed to Elizabeth Kendall, e.kendall@griffith.edu.au

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Recent shifts in health policy direction in several countries have, on the whole, translated into self-management initiatives in the hope that this approach will address the growing impact of chronic disease. Dominant approaches to self-management tend to reinforce the current medical model of chronic disease and fail to adequately address the social factors that impact on the lives of people with chronic conditions. As part of a larger study focused on outcomes following a chronic disease, this paper explores the processes by which a chronic disease self-management (CDSM) course impacted on participants. Five focus groups were conducted with participants and peer leaders of the course in both urban and rural regions of Queensland, Australia. The findings suggested that outcomes following CDSM courses depended on the complex interplay of four social factors, namely, social engagement, the development of a collective identity, the process of building collaborative coping capacity, and the establishment of exchange relationships. This study highlights the need for an approach to self-management that actively engages consumers in social relationships and addresses the context within which their lives (and diseases) are enacted. This approach extends beyond the psychoeducational skills-based approach to self-management into a more ecological model for disease prevention.

1. Introduction

With a rapid rise in the prevalence of chronic conditions and the ensuing demand placed on health services, the sustainability of most health care systems around the globe has been threatened [1]. During the last decade, the strategy of choice has been to focus on promoting healthy lifestyles and choices [2, 3], the most common method of which has been to promote self-management through the delivery of psychoeducational group programs. This approach has now become an integral component of the Australian and UK healthcare systems. Although there are multiple approaches to the promotion of self-management, the most common approach has been the Lorig [4] model of chronic disease self-management (CDSM). This model is a standardized course delivered over 6 weekly sessions of approximately 2

hours each week. Courses are delivered in community settings and usually facilitated by two trained peer leaders using a highly structured course protocol. Course content introduces participants to a range of topics pertaining to health and well-being (e.g., healthy eating, exercise, relaxation). The process emphasizes group interaction and support and reinforces solution-focused behaviors (e.g., problem solving, goal setting, communication with healthcare team and family) aimed at assisting individuals to actively manage the impact of chronic conditions on all domains of their life (e.g., emotional, physical, and social well-being).

Within this approach, health professionals are primarily responsible for the medical management of the disease or chronic condition, and the individual is responsible for the day-to-day management of his or her condition. The emphasis is on strengthening individuals' skills and confidence

TABLE 1: Focus group participants.

	No. of focus groups	No. of participants	Gender	
			Male	Female
Urban participants	2	16	2	14
Rural participants	2	11	4	7
Peer leaders	1	7	0	7
Total	5	34	6	28

about managing their chronic conditions through supportive group education and improved partnerships between individuals and their health professionals [5]. Self-management remains an individual-level concept framed within a medical model, focused on disease and deficiencies in the person which require education to enable them to comply with health professional advice [6]. In this sense, the CDSM model does not represent a radical shift from traditional approaches to healthcare.

The purpose of this paper was to identify the way in which participants and leaders of the CDSM course described the mechanisms by which it impacted on them and their health.

2. Method

Five focus groups were conducted during the national implementation and evaluation of the CDSM course in Australia. The purpose of this paper was to examine the way in which the course impacted on health from the perspective of participants (e.g., people who had completed the course within the last six months) and peer leaders (e.g., people with chronic conditions who had run a course for others in the last six months). All eligible leaders and participants who had completed a course in one of the two pilot areas were telephoned and asked to participate in a focus group. Initial contact was made by the organization responsible for the delivery of CDSM training in Queensland, Australia. Those who agreed to participate were then contacted by the research team following approval from the University Research Ethics Committee.

Care was taken to ensure reasonable representation of male and female participants from a range of differing course locations and people with a range of chronic conditions. However, as expected given the population of participants and leaders, there was a bias towards female participants and an absence of male peer leaders. All participants were over 50 years of age in accordance with the eligibility requirements established by the organization. The constitution of each focus group is shown in Table 1 and the focus group questions are contained in Table 2.

Focus groups were facilitated by two researchers and were held in the most convenient local building chosen by the leaders of the courses. The focus group discussions were introduced to the participants as having been designed to elicit their perceptions and experiences of the course. Specific prompt questions focused on their awareness and acceptance of self-management as a concept, experiences of

the self-management training (where relevant) and course leadership, interactions among participants and followup with health care providers, perceptions of sustainability of self-management, and overall satisfaction with the program. The focus groups were audio-recorded, transcribed verbatim and analyzed using a collaborative multiwave process.

Two researchers independently coded the transcripts, selecting units of text that contained information about how participants viewed the course and the way in which it had influenced outcomes. Units of text that did not contain any useful information about the course or its influence were discarded (N.B. discarded text usually contained general interactions or comments about benign topics such as the weather, the environment, and personal communications). The units of text selected by these two researchers were compared and discussed to reach agreement about the most important extracts that should be further analysed. Although a few minor pieces of text were discarded as having no meaning for the current study, the two researchers agreed that all other pieces of text should be retained.

Once this first level of data selection was complete, the reduced dataset was analysed by a third researcher to identify the major themes that existed across all selected extracts. The themes that emerged from this second wave of coding were reexamined by another researcher to determine the extent to which the categorization process was transparent and meaningful. Areas of disagreement were minimal but were addressed through discussion. If text added a useful dimension to several themes, it was used in multiple places. Any text that could not easily be categorized was reviewed. If considered by mutual agreement that the text added nothing new to the analysis, it was discarded. Themes reflected both positive and negative articulations of the concept.

To validate the findings, we presented them to a group of peer leaders and trainers as well as national and international experts in the area of CDSM. Feedback indicated that the themes accurately reflected the experience of others in the field. Direct quotes have been replicated verbatim and have been referenced using abbreviations to indicate the source (e.g., U: urban participants, R: rural participants, PL: peer leaders).

3. Results

Participants held strong beliefs about the benefits of the course (e.g., knowledge about chronic disease, self-management skills, problem-solving/coping skills, goal setting and decision-making skills). As expected, they reported that their knowledge increased as a result of the course and that this translated into an increased sense of confidence, greater control over their future, and a positive attitude towards their disease. These findings are presented in more detail elsewhere [7].

Participants in this study reported that some potential attendees had elected not to enroll in the course because they disliked group processes. Similarly, some participants failed to complete the course because they had not enjoyed the group format. This conclusion suggests the possibility of a self-selection bias towards those who valued social

TABLE 2: Focus group prompt questions.

Overall satisfaction with the program	Overall, how satisfied are you with the program? What has been the impact (if any) of the program on your life?
Perceptions and experiences of orientation, education, and training	How well were you informed about the program when you first joined? What did you know about the program before you commenced? What were some of your expectations about the program? Overall, how satisfied have you been with the training you received? Overall, how satisfied have you been with the postprogram followup? What type of support (if any) have you received after program? Are there any difficulties you experienced while participating in the program? What strategies did you use to overcome these difficulties? What kept you coming each week?
Perceived impact of the program	Has the program had an impact on the way you manage your condition/s? your lifestyle in general? How has it changed your lifestyle? What are some of the supports/strategies you have used yourself (or are necessary) to make this impact last? To what extent did the program leaders answer your questions? To what extent do you feel that the program leader gave you adequate information about your condition/s? Overall, how would you describe the quality of the program leader

exchanges. Nevertheless, there was little doubt that those who attended the course attributed their gains to the social context of the course. Specifically, self-management appeared to evolve through, and was situated within, a network of social exchanges and support processes that were facilitated by the course. Indeed, the majority of participants who completed the course discussed social processes more often than course content, indicating the importance of these processes to their evaluation of the course. Participants' level of satisfaction with the social processes of their particular group also seemed to be critical to their overall impression of the course. There was evidence that without this contextual feature of the course, the benefits may have been less meaningful to participants. Further, there was evidence that when social processes were negative, the benefits of the course were jeopardized.

The four major social themes that emerged described the importance of the social context to the success of the CDSM course. These themes included

- (i) social engagement;
- (ii) a collective identity;
- (iii) collaborative coping capacity;
- (iv) exchange relationships.

3.1. Social Engagement. An overwhelming theme in the data was the benefit derived purely through social engagement. Participants usually referred to the course as an opportunity for social interaction and described how this interaction addressed the long-term loneliness or social isolation associated with having a chronic condition.

In most cases, the group provided a friendly context within which people learned about each other's experiences but felt no pressure to divulge personal information. This common experience enhanced the likelihood of supportive friendships emerging, even if only temporarily.

I found it helpful to mix with people who had similar problems, even though they had different diseases. It was just so supportive (PL).

You make friends with people that go through similar pain as you. Each one of us identified with it (R)...It is the best thing that ever happened to me. Because you make friends and we do not see each other all the time but it is just nice to see their faces again (R).

Having the time and opportunity to socialize with other group members before and after each session was considered to be a valuable aspect of the course for most participants. Their comments indicated that a great deal of satisfaction accompanied these opportunities for social contact.

So when we first arrived which was always good, if you were there a few minutes early you could have a cup of tea...it was really nice to have a drink and a conversation just for five minutes (U).

In many instances, the chance for social interaction was a major source of motivation not only to join the CDSM program, but also to continue attending sessions and participate in activities designed to impart information and skills.

It [course] was the chance of getting out...It does not matter what the group is, it's the

social interaction [that matters] (U)...As we went along, we got friends and you know we all joined together (U).

The value placed on social engagement was demonstrated in the actions of several participants who made the effort to maintain regular contact with other group members once the course had ended.

We all meet up once a month now and have lunch together and we are going to try and keep it that way (U)...At the follow-up meeting people had actually kept in touch with each other. They seemed to find that very helpful (PL).

Many participants reported that the CDSM course was a significant opportunity to address social isolation. The course not only provided social opportunities, but, enabled them to reevaluate their own self-isolating behaviors and choices.

There's a lot of people who do these courses who are very lonely (U)...I'd done like a similar sort of course. I thought well, it's one way of learning more, and um, and meeting people (U).

We try...and promote the fact that there is social life ahead for you too, we [people with chronic conditions] have a reluctance to even go outside, to catch a bus. I hated to go down to the letterbox because somebody would see me and I would have to talk (PL).

There's that opportunity for social interaction that's important for many people. Because people do tend to feel a bit isolated do not they? Or it's perhaps restricted. It does not matter what group it is. It's the social interaction with it [that matters] (U).

To know that there are other people there and there is a social life...encouragement to do something that we needed more than anything else [to meet people] (R).

In cases where participants' expectations for socialization were not met through the course, the perceived benefits derived by those participants appeared to be reduced, "I think I was hoping for it to be a little more social for people, like a little more friendly" (U). Similarly, when participants were dissatisfied with their group, it was often attributed to a lack of social engagement or bonding among participants.

Nobody was sort of friendly or wanted to [get to know each other]...It was a really mixed group of people...I did not feel, like if you had a "cuppa" afterwards there wasn't much talking going on and they did not talk from the way in from the car park. We went out to lunch the last day but...they really had to be forced into it (U).

These findings suggest that the benefits of the course which have previously been attributed to cognitive or educational processes may be equally attributed to the simple process of social engagement that was facilitated by the group setting. There was a dual benefit of social engagement in that it motivated participants to initially engage in self-management but also to continue learning.

3.2. A Collective Identity. Positive changes in confidence and attitude following the course appeared to be associated with the sense of belonging to a cohesive group of people. The cohesion of the groups provided an immediate opportunity to identify shared concerns, to normalize one's difficulties, to gain a sense of accountability to the group, and to be guided by the norms that had been set by the group. This sense of belonging provided a collective identity that encouraged people to view themselves and their situation differently.

A large number of participants commented on the importance of group composition and dynamics to the success of the course and its benefits, "I think a lot of it has to do with the people who are in the class" (R). Participants who felt that their group had lacked cohesion reported that this had impacted negatively on their satisfaction and achievements.

The class was excellent, the only thing that I thought about it was that I felt a bit out of it—they [other participants] have all got these beautiful homes, beautiful spas and beautiful pools and exercise bikes. The whole works, and I am coming from a rather grotty home and I would have loved to have lived in their circumstances, I felt life could have been a lot easier. But they were sort of, they all knew each other, it was a bit "clicky" in some ways, I felt it...They were all friends, they all knew each other very well and...In comes a couple of outsiders...(U).

The crucial importance of group membership was summarized by several participants, who pointed out that any group might bring similar benefits if a sense of cohesion could be achieved.

Any group therapy helps you though...it is just a case of getting together and finding other people...You are not on your own (R)...I'm just one of many people with a problem and by coming together as a group you talk and it gives you another outlook on life. You think you're in that one little square, but...there's other people in that little square too (R).

For most participants, the fact that they were "...answerable to somebody" was an important source of motivation, because of knowing that "somebody is sharing an interest in you ... [made you]...more inclined to respond" (R). For some participants, however, the pressure of being scrutinized by a group compelled them to offer socially desirable responses during feedback sessions rather than admit that they had not achieved their weekly goals. Thus, the influence of the collective on individual behavior was both positive and negative.

The lady I took [to the course], on the way I would say, "How did you go with your weekly plan?" and she would tell me, "I did not do anything" and then we would get there and she would say "Oh yes I [completed my action plan]" (U).

Participants generally agreed that the group norms (e.g., sharing goals and reporting back) meant "you had that incentive...you had to go back and say when you had done it" (U). Participants who had not attended to their course requirements (e.g., goal-setting homework) commented that "...you really felt you were letting the team down to some extent if you did not at least try" (U). For one person, it was "like a promise, and you find when you are not there [part of a group] you do not really do it" (R). Indeed, being a member of a cohesive group instilled motivation for most members to achieve their weekly action plans, "Over the period of time, I think the group helped one another to try to keep with their activity sheet" (R).

In summary, our findings suggested that the CDSM group context provided an important opportunity for social comparison, normalization, and a sense of belonging. These benefits appeared to be only achievable through a cohesive group where members shared experiences, motivated each other, and provided opportunities for discussion. When members felt they did not belong, or were unable to meet expectations, the outcomes of the course appeared to be less positive.

3.3. Collaborative Coping Capacity. Participants frequently commented on "the supportiveness of the group, it was very supportive" (U). Most participants were in agreement that, "when around the table with other people...one on one... [it was] much easier to cope with your pain" (U). Attendance at the group appeared to be associated with increased coping capacity for many participants. The belief that one's coping efforts were being supported and appreciated by others in the group was an important positive outcome for most participants.

However, this effect appeared to have broader implications in that coping became a collective response to a public issue rather than a private response to a hidden problem. With this new approach to coping, many participants gained renewed enthusiasm and energy, facilitating their engagement in self-management. Although it was important to participants to develop more confidence to manage independently, they also identified the need for, and importance of, collective management. For many participants, collective spirit and individual confidence appeared to coexist and complement each other.

Number one [e.g., the most important thing] is better confidence in yourselves [but also] the fact that they're not isolated in their condition and that other people share similar things (R).

The shared experience of being with people who have had similar issues has given them [participants in the course] confidence to tackle stuff that they previously wouldn't have done...they are

breaking out of the sick role into more lifestyle issues (U).

Through their shared experience of coping, private pain became a collective experience and was, therefore, perceived as being easier to manage, "I was not the only one in the community going through pain and disability" (R). The collective environment provided the necessary opportunity to express fears, concerns, and issues in a way that had not been experienced before. This experience profoundly affected participants' connection to the group and their sense of solidarity as they confronted the shared threat of chronic illness.

I had been to lots of these things [courses] and they left you feeling wrecked...what I found with these meetings is how relaxing they are, how easy it is to gather information. People are given opportunities to be able to speak or express their feelings and where you are given opportunities you are given choices and there is no pressure put on anybody to perform. It is just about people wanting to help somebody else through their daily lives (R).

The group connection was an important starting point for a collective coping response because group members tended to track each other's coping efforts over time and celebrated the successes as a collective.

[It is good] to see how we are growing, in ourselves you know. How we are coping with our lives, yes it [the group] is very important (R).

Conversely, participants described how the presence of negativity in the group impacted on the prevailing collective attitude and had negative consequences for their own psychological well-being and experience, "A lot of people did their weekly plan [only with] prompting...they never did it [alone]"; "they would make excuses" (U). The lack of motivation in other group members had negative consequences for several participants. "[It] made you feel depressed", "oh yes, I did too, I got depressed too" (U). One participant explained how negativity and lack of motivation in other group members influenced all members of the group:

Some of the people had given up you know just sort of given up and said, "I just cannot do this" ...and you just sort of felt, "Am I going to be like that down the line"? (U).

In contrast, one participant explained how exposure to unmotivated individuals fortified her determination to cope and successfully manage her condition in future. The collaborative process motivated this participant to resist the negative influence of another participant, identifying that participant as a deviation from the norm and finding motivation to avoid similar outcomes for herself.

Like I said, once I got out of the group and sort of finished the course, I just sort of kept saying to myself, "There is no way I am going to end up like that, there is no way I am going to end up like that" (U).

This theme described the importance of coping as both an individual and collective process. Participants reported interacting with each other in complementary ways to facilitate better outcomes for all participants. The coping capacity of the entire group influenced individuals and shaped the strategies they applied beyond the group context.

3.4. Exchange Relationships. The process of learning from others, swapping ideas within the group, and sharing information about resources was vital to improvements in confidence, sense of control, and positive attitudes. Essential exchange relationships operated throughout the course, and for some participants, continued after course completion. Participants were inspired not only by their capacity to learn from others, but also by their capacity to share with others. The opportunity to provide information as well as gain information from others was a mutually satisfying activity. This two-way learning process was crucial and encouraged participants to conclude that the course was an important adjunct to the current range of available resources

Doctors just say go home and look after yourself. . .whereas if you know there's a group you can go to [the course] and their [other participants'] ideas are so important because one of the persons in that group might have had an illness before and know how to handle situations (PL).

If I can swap something that suits me with somebody else and make it a bit of a benefit out of it then that's the idea of these little groups getting together (U).

All participants reported sharing resources with each other, indicating the universal nature of this exchange function. Most participants appreciated the exchange of ideas and resources among the group members because it enabled new learning to take place for all parties. It encouraged group members to examine their own role in society and feel that they had contributed to the well-being of others.

You might have a certain problem, but if you start talking to one another, "Oh yes I had that and this is how I got around it". In other words, it is a swapping of thoughts (R).

And so, to know that there are other people there and there is a social life for encouragement . . .that there is a place for us within the community. Not so much. . .help because I did not realize I needed help, but I'd like to think that my life is [now] a bit more worthwhile (PL).

The deliberate creation of dyads who could motivate each other and promote the exchange of ideas was useful to many participants. However, there were examples where this "buddy" system did not work well, because not all participants valued such intimate exchanges with another person.

Nobody did it [called their buddies] and I felt really silly because I got the attitude when I did

ring that I was a sticky nose that I was interfering. I got that impression from them (U).

I wouldn't participate in that [buddy system] because I am not that kind of person. I'm not a buddy person like that. . .I mention that because there might be a few other people like me and do not participate in that. I should imagine it works for a lot of people. But I am afraid I am just not that person (U).

Indeed, the potential for conflict within dyads was evident. One participant relayed a negative encounter that occurred during a session requiring group members to pair up and discuss negative emotions. This experience highlighted the importance of exchange systems that emerged naturally within the broader group process as opposed to forced dyads that could result in damage to one of the parties if the exchange was not mutual.

As far as the other people went, we had a major problem with the first or second week, I forget which one. One of the ladies came and she was next to me and I turned around and said to her, "Well would you like to tell me your problems", because that is what we were meant to do [for the activity], and she attacked me. Really attacked me, as if I wouldn't know what a problem was and she had the worst problems and things. I wouldn't have gone back except that they [leaders] said, "Well she [the woman who had been defensive] is not coming back, she is obviously not right for the course". So I thought, "Oh well", I had promised to take [friend] every week so I was forced to go because I had committed myself (U).

The social rather than interpersonal nature of the group was also highlighted by the fact that participants most commonly reported gaining benefits from processes that engaged the entire group. These activities were viewed as an effective mechanism for social exchange, "All the work was done on the [white] board and we could all participate" (U). Participants recognized that practicing new techniques in the group setting, rather than just discussing them, was an important part of the learning process. They noted the values of the immediate performance feedback that could be gained from other participants.

They were not just actually telling you about it, they got you down [doing the techniques]. It must make a difference if they take you through it (R).

We all got to see each other [practice the techniques]. . .I think there was interest and hoping that we would learn something and, be entertained too (U).

You learned something and you were also with a group of people, you know, you weren't just a single person; you were going to learn from others; You exchange experiences, you learn from other

peoples' way of coping that you hadn't thought of and sometimes you hear much worse problems than your own too and how the other people coped with them (U).

This theme revealed an important social exchange function of the course. Instead of relying only on the information provided through the standardized course content, participants sought a two-way exchange of ideas and social comparison with other participants. This process enabled them to find new strategies, resources, and processes that helped them to manage their conditions. They also gained from the opportunity sharing their successes with others. However, this social exchange process differed from the interpersonal support that might be received through a closer relationship with one person.

4. Discussion

The central argument developed and presented in this paper is that, far from being an individual concept situated in the private lives of people with chronic conditions, self-management is better understood as a social concept embedded within and facilitated by collective processes and supportive systemic contexts. Over the last decade, increasing emphasis has been placed on the social context within which an individual with a chronic condition is located and the important role of social supports, service infrastructure, and social connections [8]. Despite the importance of individual disease treatment, we have previously drawn attention to the limitations of an individual model of self-management [6]. We have also argued that if inadequate attention is given to the social and environmental factors that can facilitate or inhibit health, self-management efforts may be wasted [9].

Our conclusion is further strengthened the key themes that emerged through this analysis of the process by which participants and peer leaders described the impact of the course. Specifically, this study has demonstrated that the social aspect of the group was a crucial factor in the success of the course and that benefits were associated with the interaction of four main social processes. The social context of the course created an environment characterized by collaborative coping, shared learning, and belonging. Most importantly, the course provided a solution to the social isolation that was experienced by many people with chronic conditions. According to participants, these features were linked to the successful outcomes of the course.

This study confirms the raft of evidence that social support is a critical buffer, potentially mitigating the impact of a disabling condition, ameliorating anxiety, and enhancing quality of life [8]. Indeed, there is evidence that high levels of social support are associated with better self-management behaviors [10]. The importance of combining educational and social processes has been found elsewhere [11], suggesting that, although any social gathering might facilitate similar positive outcomes, the course provided the structured interactions that enabled participants to engage in positive ways (e.g., to develop collaborative coping and a collective identity). Choi et al. [12] noted that group members are

exposed to two types of influences: (1) discretionary influences that are available to different group members at different times and in different forms as they interact with other group members (e.g., messages of approval, learning, etc.) and (2) ambient influences that are available to all members and pervade the group setting (e.g., group norms, positive climate, shared ideas, etc.). The current study has articulated these different influences, noting the presence of both ambient (e.g., a collective identity and collaborative coping) and discretionary qualities (e.g., social engagement and exchange relationships).

Despite being delivered in a group setting, the dominant conceptualization of self-management is an individual approach and framed within a medical model. Self-management in this context is defined by three key premises, namely:

- (i) the individual is perceived to be dealing with the consequences of disease;
- (ii) the individual is perceived to be deficient in skills such as problem solving, decision making and self-confidence;
- (iii) the individual is placed in partnerships with a health professional who takes responsibility for medical management [13].

In contrast to this conceptualization, the current study has suggested that self-management is a social concept and that several important social processes might be able to account for the outcomes achieved through CDSM courses. This analysis has defined a "social" model of self-management that may be more sustainable and relevant than the current individual model of self-management. By giving adequate attention to the social aspects of self-management, it is likely that the utility and meaningfulness of the course could be enhanced for a significant proportion of the population.

Self-management as a social concept goes beyond individual interventions and even beyond partnerships with health service providers. It may be better conceptualized as a collaborative concept enacted when individuals come together, although not necessarily in a physical place. The act of coming together creates greater capacity to address the "collective" problems associated with chronic disease. The process of self-management seems to be about sharing approaches to common problems, building resources together, encouraging and motivating each other and transforming private pain into collective responses that would never have emerged in an individualized setting. Thus, health professionals may need to refine their understanding of and support for the social processes that contribute to and sustain self-management outcomes.

The process of social self-management that emerged from this study resembles the notion of cultural health capital [14]. According to Shim [14], cultural health capital accrues as one engages in the repeated enactment of health practices (e.g., consuming information, decision making, self-surveillance, etc.). Thus, cultural health capital has a self-generating quality, accumulating over time through

interactions with others. This concept is embedded in social processes and is inherently relational. Rather than placing demands on people to become independent and self-directed managers of their own health through education, the notion of self-management as a form of cultural health capital acknowledges that self-management relies on interdependence and builds over time as people engage with new practices and ideas.

5. Conclusions

The findings of this study revealed that responses to disease and ways of self-managing were clearly situated not only in the private lives of individuals, but also in collective processes. Individuals were encouraged and motivated by the social interactions, engagement, and support they received from coparticipants. These findings suggest a dynamic and multidimensional approach to health and well-being which recognizes the role of context and relational aspects of people's environments. Although not surprising, the current study highlights the fact that the dominant interpretation of self-management adopted by many health professionals may be overly simplistic. The focus on skills, resources, and education about health overlooks the importance of building opportunities to enhance one's cultural health capital through positive social interactions. Our study has suggested that there may be sufficient reason for policy makers and professionals to become concerned with activities and interventions that develop supportive social environments and opportunities in addition to their current focus on lifestyle change at the level of the individual.

However, such a shift will not be easy. Recognition of a social model of self-management will require a fundamental reorientation of professional practice. First and foremost, it will require a shift from the individualistic educational model of self-management towards one based on the application of broad social strategies that can create conditions that foster hope, healing, empowerment, and social connection as well as a positive culture [15]. This shift will require a commitment to new ways of working with clients that reflect the social context within which they function. If health professionals can be encouraged to think about self-management as a form of cultural health capital, accumulated through a vast array of social interactions, they may be able to not only support the social processes that facilitate self-management, but also enact their own role in ways that act as a source of self-management support. The CDSM course appears to be a useful vehicle for facilitating the social processes that emerged from our data. However, it may be possible to promote these social processes more widely within all clinical interactions if a more social view of self-management was propagated. A continued focus on self-management as an individual responsibility that is reliant on the skills and knowledge residing within the individual will encourage health professionals to overlook the social and contextual nature of the concept. It will also enable them to minimize the importance of their own role as a social agent and a facilitator of social processes.

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Review Article

Patient Engagement as an Emerging Challenge for Healthcare Services: Mapping the Literature

Serena Barello,¹ Guendalina Graffigna,¹ and Elena Vegni²

¹ Faculty of Psychology, Università Cattolica del Sacro Cuore, Largo Gemelli 1, 20143 Milano, Italy

² School of Medicine, Università degli Studi di Milano, Via di Rudini 8, 20142 Milano, Italy

Correspondence should be addressed to Serena Barello, serena.barello@unicatt.it

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Patients' engagement in healthcare is at the forefront of policy and research practice and is now widely recognized as a critical ingredient for high-quality healthcare system. This study aims to analyze the current academic literature (from 2002 to 2012) about patient engagement by using bibliometric and qualitative content analyses. Extracting data from the electronic databases more likely to cover the core research publications in health issues, the number of yearly publications, the most productive countries, and the scientific discipline dealing with patient engagement were quantitatively described. Qualitative content analysis of the most cited articles was conducted to distinguish the core themes. Our data showed that patient engagement is gaining increasing attention by all the academic disciplines involved in health research with a predominance of medicine and nursing. Engaging patients is internationally recognized as a key factor in improving health service delivery and quality. Great attention is up to now paid to the clinical and organizational outcomes of engagement, whereas there is still a lack of an evidence-based theoretical foundation of the construct as well as of the organizational dimensions that foster it.

1. Introduction

Patient engagement is nowadays more and more recognized as a crucial component of high-quality healthcare services [1, 2]. In the majority of the Western countries, patient engagement in health and social care policies is well established with the government commit to foster interventions and research projects and methodologies which prioritize the "patient's voice" and the "patient's active roles in their own healthcare" [3, 4] as it leads to more responsive services and better outcomes of care [5]. In the last years, patient engagement has gained increasing prominence thus providing an impetus for research programs and initiatives encouraging individuals and communities to have a stronger voice in National Health Services, as it seems to contribute to gain better health outcomes, to enhance patient's care and cure experience, to improve illness self-management and adherence to therapies, and to reduce care costs.

From a nursing perspective, in particular, the need to give patients better and reliable information and more control and influence over their healthcare was particularly

emphasized. By building partnership with patients and families and fostering their engagement in the process of care, nurses can develop an appropriate plan of care and cure addressing issues such as symptom and drug management and meaningful discharge goals [6]. The role of nurses constitutes a core component in the organizational aspects of care such as care coordination, continuity of care, and health information exchange: this may support the attainment of optimal, patient-centred outcomes defined by a care planning process driven by a robust partnership between nurses, physicians, and patients. Underlying these statements is the belief that engaging patients may improve patient satisfaction toward received care, cooperation and partnership with health providers, better management of the disease, increased trust, and enhanced patient-professional relationship [7]. The nursing community historically acknowledged the importance of engaging patients in the healthcare clinical encounter and in the disease management by organizing and implementing care to meet the individual's needs: however, to gain this goal, nurses have to allow patients to be engaged in their care in order to perceive their needs

to be important and legitimize their expressions [8]. The consequences of nonengagement may include preventable illness and suffering, suboptimal health outcomes, increases in health disparities, and wasted resources [9].

Despite the growing popularity of the terms and the increasing attention toward this concept by researchers and policy makers, there is a little consensus about what patient engagement means. In order to address this lack of shared knowledge, this paper aimed to:

- (1) provide a quantitative overview of the publication trend on patient engagement from 2002 to 2012 in the whole and across different academic disciplinary fields and countries;
- (2) provide a qualitative analysis of the most cited academic articles in the field (the 10 most cited articles from 2002 to 2012) in order to better understand the concept of patient engagement and discuss the aspects (i.e., definition of patient engagement provided, characteristics of the study, etc.) which probably make these contribute so relevant into the scientific debate.

2. Materials and Methods

Analysis of the cooccurrence of the terms “patient” & “engagement” appearing in keywords, titles, and abstracts within the health academic and managerial literature was conducted on June 17st, 2012, using the electronic databases more likely to cover the core research publications in health issues (ISI Web of Science, Medline, PsychINFO, SCOPUS, Google Scholar) across medical, scientific, psychological, and social scientific sources. Together these databases allow to retrieve publications from the major academic and managerial journals across hundreds of scientific disciplines which have contributed to research on patient engagement. We decided to search articles which only included the terms “patient engagement” and not close concept (i.e., patient participation or involvement) in order to maximize sensitivity and conceptual clarity. Only research articles where the abstract was available were considered. Moreover, a study was eligible for inclusion in the analysis if in the abstract it describes (a) patient engagement generally, (b) intervention to promote patient engagement, (c) determinants of patient engagement or (d) outcomes of patient engagement, and (e) measures of patient engagement. The search was conducted within the peer-reviewed English-written literature in the last ten years for the period from January 2002 to June 2012. Articles from non-English-written journals were excluded.

We answered to aim 1 by doing bibliometric analysis on different aspects of publications’ trend; aim 2 was addressed by conducting a qualitative content analysis on some selected articles.

- (a) Bibliometric analysis of the articles retrieved from all the databases were performed in order to portrait the trend of published articles within the academic and managerial fields.

- (b) A deeper quantitative bibliometric analysis was conducted on the mere academic production subcorpus (i.e., articles from peer review journals with IF) in order to detect disciplines and countries more “productive” in the ongoing debate about patient engagement. In this case, we chose to analyze only the research articles indexed in the Scopus database as it provides the wider amount of publications (in comparison to the other academic databases)—see Table 1—and allows to cover all different disciplines involved in the health research, whereas Medline and PsychInfo are more discipline based [20, 21]. (In comparison to Isi Web of Science, Scopus has almost 28 million records against the 19 million of Isi Web of Science and covers over 15,000 journals versus 9,000 in Isi Web of Science [22]. Scopus allow to extract the academic field more responsive to patient engagement issues by mapping and labeling the articles under consideration basing on the judgment of a pull of expert in the health sciences. The specific academic field which each article belongs to was based on both Scopus pull of experts’ judgment and a manual qualitative revision of the abstract of the ambiguous ones by one of the author (SB). The “create-citation report” tool was used to obtain detailed data on citations to the retrieved publication).

- (c) Finally, the search results were exported in text format: this allowed one of the authors (SB) to analyze in depth the 10 most cited articles (themes and features) and to conduct a qualitative content analysis [23].

3. Results

3.1. Bibliometric Analysis. Descriptive bibliometric analysis of retrieved data was performed to analyze the quantitative trend of publications about patient engagement—over the 10-year period considered—taking into account the number of academic and managerial articles provided by all the databases. Data showed a general increasing interest toward patient engagement both in the academic and managerial fields. This is clearly shown by the growing trend of published items over the considered period (Table 1). The number of publications per years indexed by all the used databases clearly highlights a progressive increase in the yearly number of publication related to this area.

The academic fields—in terms of article-related contents—that are more involved in publishing on patient engagement are medicine, which covers the 69, 1% of the entire corpus of publication on this theme, followed, in percentage, by nursing (16, 2%). Psychology and social science academic production follow with the 9, 6% and the 5, 1% of the total amount of publications, respectively. Furthermore, the trend of publication across disciplines per years displays a general growing interest around the topic in particular in the medical and nursing literature; in contrast, the contribute of the psychological research appears as

TABLE 1: Number of publications across years and databases.

Year	Electronic databases					Total	
	Medline <i>N</i>	Psychinfo <i>N</i>	Scopus <i>N</i>	ISI Web of science <i>N</i>	Google scholar <i>N</i>	<i>N</i>	%
2002	4	4	3	2	61	74	1,7
2003	6	4	5	5	102	122	2,9
2004	8	3	5	5	87	108	2,5
2005	10	7	9	6	121	153	3,6
2006	11	9	11	8	176	215	5,1
2007	16	8	19	13	244	282	6,7
2008	27	14	23	19	316	399	9,4
2009	27	11	17	13	445	513	12,2
2010	43	19	47	39	652	800	19
2011	66	23	46	40	779	954	22,7
2012*	[56]	[6]	[32]	[26]	[479]	[599]	[14,2]
Total	162 [218]	96 [102]	185 [217]	150 [176]	3261 [3740]	3620 [4219]	100

*2012 is reported but not considered to discuss the findings as data are related only to the period from January 2012 to June 2012. The amount of publications including 2012 is reported in square brackets.

TABLE 2: Number of publications by year and by discipline.

Discipline	Number of publications per year											Total <i>N</i>
	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012*	
Medicine	3	4	5	6	8	12	14	13	24	39	[29]	128 [150]
Nursing	2	1	1	2	2	3	3	5	6	4	[6]	29 [35]
Psychology	0	5	5	2	2	1	1	0	1	1	[1]	20 [21]
Social science/health policies	0	2	1	2	2	4	4	2	2	8	[3]	8 [11]

*2012 is reported but not considered to discuss the findings as data are related only to the period from January 2012 to June 2012. The amount of contributions including 2012 is reported in square brackets.

decreasing from 2004 up today. For more detailed data, see Table 2.

Focusing on the academic articles provided by Scopus, the number of publications by countries, considering the first author’s affiliation, highlights the US predominance in publishing about patient engagement related topics with an amount of 104 publications (48, 2%) in ten years, thus contributing around to the half of all publications about patient engagement listed in Scopus. Altogether, academic production of authors belonging to other countries covers the remaining amount of publications. Further details about the number of publications by country can be found in Figure 1.

3.2. *Qualitative Content Analysis.* Qualitative content analysis of the abstract of the ten most cited articles published from 2002 to 2012 was conducted in order to give a general overview of the most common research topics related to patient engagement and to provide a preliminary suggestion about the underlying dimensions of patient engagement thus

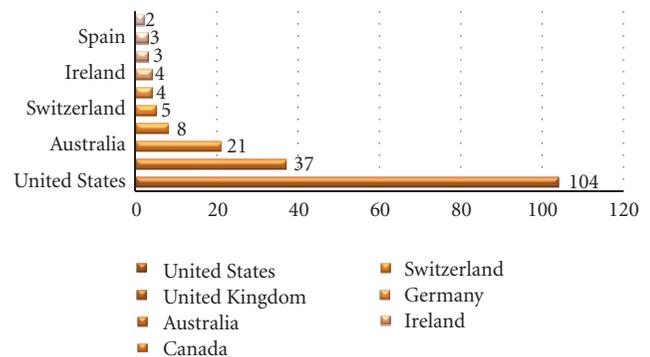


FIGURE 1: Number of publications by country first authors’ affiliation.

aiming to lay the foundation for a shared definition (see Table 3).

Patient engagement appears as a fragmented concept lacking of a unique definition: in some papers it is described

TABLE 3: Ten most cited publications from 2002 to 2012 (* the double labeling is due to the discipline label assigned by Scopus reviewers).

Number of citations	Author(s)	Title	Year	Source	Discipline*	Definition of patient engagement	Reference
188	Lehman et al.	Assessing organizational readiness for change	2002	Journal of Substance Abuse Treatment	Medicine	Engagement as <i>actions</i> individuals perform in terms of <i>adherence to drug prescription</i> and a key component for <i>high-quality</i> healthcare services	[10]
120	Simpson	A conceptual framework for drug treatment process and outcomes	2004	Journal of Substance Abuse Treatment	Medicine	Engagement as a factor which enables <i>patient alliance</i> with clinicians and <i>enhance recovery experience</i>	[11]
119	Davis et al.	A 2020 vision of patient-centered primary care	2005	Journal of General Internal Medicine	Medicine	Engagement as a <i>key component</i> to foster <i>patient-centred medical approach</i>	[12]
73	Hibbard et al.	Do increases in patient activation result in improved self-management behaviors?	2007	Health services research	Nursing/social science	Engagement as a <i>behavioural activation</i> related to healthy behaviours and positive health outcomes	[13]
49	Roy-Byrne and Wagner	Primary care perspectives on generalized anxiety disorder	2004	Journal of Clinical Psychiatry	Medicine/psychology	Engagement as a <i>crucial element</i> in <i>health policy making</i> to deliver effective and high-quality healthcare interventions	[14]
42	Casale et al.	ProvenCareSM: A provider-driven pay-for-performance program for acute episodic cardiac surgical care	2007	Annals of surgery	Medicine	Engagement as <i>behavioral activation</i> that contributes to reduce resource abuse and improve health outcomes	[15]
41	Trotti et al.	Patient-reported outcomes and the evolution of adverse event reporting in oncology	2007	Journal of Clinical Oncology	Medicine	Engagement as a <i>measurable marker of patients' compliance</i> to therapies and <i>symptoms' management</i>	[16]
32	Franklin et al.	Patients' engagement with "Sweet Talk"—a text messaging support system for young people with diabetes	2008	Journal of Medical Internet Research	Medicine	Engagement as a <i>cognitive, behavioural, emotional, and social construct</i> which foster patient's self-management	[17]
31	McCracken	Social context and acceptance of chronic pain: the role of solicitous and punishing responses	2005	Pain	Medicine/psychology	Engagement as a <i>behavioural activation</i> useful to better control and manage illness symptoms and emotional-related alterations	[18]
30	Villagra	Strategies to control costs and quality: a focus on outcomes research for disease management	2004	Medical care	Nursing/social science	Engagement as a <i>measurable marker of clinical results</i> and organizational factor which contributes to <i>reduce healthcare costs</i>	[19]

as a set of healthy behaviors which individuals should perform in terms of adherence to drug and therapeutic prescriptions [10, 16]: patient engagement, in this sense, constitutes a measurable behavioral marker of patients' compliance to therapies and their ability in managing symptoms. Other authors described engagement as a cognitive (i.e., knowledge and illness beliefs) or a relational (i.e., the quality of patient-clinician encounters) factor which influences patient's emotional experience with healthcare delivery and fosters patient alliance with clinicians [11–13, 15, 17, 18]. Finally, in some contributes, patient engagement is considered more generally as an organizational feature that constitutes a crucial element in health policy making to deliver effective and high-quality healthcare interventions as it seems to reduce waste of resources, health service abuse, and improve health outcomes [14, 19].

4. Discussion

The increasing attention to patient engagement and related topics is clearly shown by the growing number of publications from 2002 to 2012 thus suggesting that empowering patients to take an active role and to be engaged in their care has been internationally identified as a key factor in the drives to improve health service delivery and quality [24]. Moreover, it is interesting to note that all the academic communities involved in health research share an interest in studying patient engagement as a core condition in performing effective chronic illness coping and management [25]. These data are relevant as they foster the need to critically assess the specific application of patient engagement to the health services specificities. The predominance in the number of publications within the medical and nursing areas may suggest that these fields are probably the most responsive to the debate on patient engagement by including it in the research agenda and, at the same time, by producing insights in order to implement change in healthcare organization processes [26, 27]. Regarding the trend of publications split by discipline, even though there is a general increasing of academic production over the years, in the period from 2002 to 2005, we can observe a prominent focalization on the mental health context which implies a conceptualization of engagement as alliance between patient and clinicians as a key factor in promoting treatment effectiveness. In the last years, from 2006 to 2012, a more specific focus on organic patients' care (by medical and nursing perspectives) provided evidence about the need for developing interventions to improve disease-specific self-management behaviors, such as medication, adherence, and condition monitoring in order to better allocate resources to manage the whole patient population. This shift in the ways of conceptualizing patient engagement does not facilitate the formulation of a shared definition across scientific communities thus supporting the idea that a comprehensive definition is a challenging but urgent task. Furthermore, the efforts in encouraging greater patient engagement seem to be founded, up to now, on research more focused on expected pragmatic impact on patients' health obtained by active partnering with them

and not on the organizational process which sustains its achievement: as a consequence, the current academic debate seems to reveal a stronger interest in the clinical and organizational outcomes of patient engagement (may be due to the need for legitimizing it as a healthcare priority) [12, 19]. However, little importance is till now given to cast light on the intrinsic nature of engagement: despite the growing popularity of the term patient engagement in the everyday rhetoric of worldwide NHS—especially in the English-speaking countries—it remains conceptually underdeveloped. Few attempts to find empirical markers of engagement have been conducted [9, 28], probably due to the still fragile link between the empirical evidence and the theoretical foundation of this construct. As a consequence, in order to develop a robust evidence-based theoretical framework and to enable data comparison and evaluation to be made, there is the need for a common understanding of what is meant by patient engagement in practice and how it can be operationalized and measured.

The multifaced definition of patient engagement emerging from our data suggests the hypothesis for which this concept may have some unchanging and underlying dimensions that are discipline-unrelated and operationalizations that are, instead, idiographic and context based. Probably, patient engagement may be observed from multiple perspective thus suggesting the opportunity to reflect upon the interaction between its individual (i.e., emotional, cognitive and behavioral, etc.), relational (i.e., patient-health providers, patient-caregiver, patient-patient, etc.), and organizational (i.e., type of healthcare settings, admission process, shape and process of intervention, use of ICT, role and attitude of health professionals, etc.) dimensions across the specificities of each single disease. A recovery of a psychological view seems also to be necessary, in order to give a comprehensive theorization which may take into account the individuals' role in being engaged in their care as subjects involved into a relational context and into a specific health culture: this may lead to build an inductively founded theoretical framework based on empirically rooted data. Surely, to take into account the patients' perspective on their own engagement may be particularly relevant in order to better assess the full range of factors that may be involved in such engagement and to foster a more effective use of healthcare services [27]. Given the complexity of the phenomenon and the relevance of its practical implications, our study may suggest that there is a pressing need for empirical research to deepen the components of patient engagement at various levels (individual, relational, organizational, etc.), their specific impact and their interconnection [28]. Once these issues are addressed, targeted interventions could be developed and implemented.

On the other hand, the contributions of nursing research in valuing the central role of nursing practice in enhancing patient's engagement in the process of care should be encouraged. Nurses are often portrayed by patients as the health providers who most make them feel as full engaged partners in the process of care [29]. The input of nursing research in highlighting factors which may shape the possible forms of patients participation really attuned to each patient's

needs may offer useful insights to plan interventions which maximize opportunities for patients to take an active part in their care, if they so wish.

In order to gain these aims, we think that to assemble a detailed picture of the underlying components of patient engagement is particularly urgent: this may allow to offer a holistic vision on patient engagement which takes into account its multidimensional nature which could better enable strategic tailoring and targeting of interventions to support the capacity of health organization to be “engager” and to make patients “engaged” in the care process. Finally, engaging patients in interventions which develop their skills and confidence in self-management might be a key strategy in order to address the necessity of policy makers for seeking ways to rationalize the use of resources in an effort to deal more effectively with long-term chronic conditions and disabilities [30]. The growing claim for patients that are fully engaged and mobilized should be not only a declaration of intent, but also a strategic resource which could transform the quality and sustainability of health system [31]. The implications of this study are likely to have relevance for international patient engagement intervention and to gain insights into its related body of knowledge in order to open viable avenues for further research.

4.1. Limits and Future Research Developments. This bibliometric exploration offered an interesting picture of the ongoing debate about patient engagement. However, further analysis is needed in order to deepen the definition of patient engagement and to systematically meta-analyze results achieved on the topics by scholars across disciplines [32]. A deeper consideration of pathological areas and of how these impact on the different conceptualizations of patient engagement is also opportune. Moreover, empirical research is needed in order to ecologically explore what means for patients to feel engaged in the care and cure process and to collect stories and experiences of healthcare intervention fruitions that appeared successful in improving their engagement.

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Research Article

Preparation and Support of Patients through the Transplant Process: Understanding the Recipients' Perspectives

**Oliver Mauthner,¹ Enza De Luca,¹ Jennifer Poole,² Mena Gewarges,¹
Susan E. Abbey,³ Margrit Shildrick,⁴ and Heather Ross⁵**

¹ Cardiac Transplant Program, University Health Network, 585 University Avenue, NCSB 11-G31, Toronto, ON, Canada M5G 2N2

² School of Social Work, Faculty of Community Services, Ryerson University, 350 Victoria Street, EPH-220, Toronto, ON, Canada M5B 2K3

³ Department of Psychiatry, University Health Network, 585 University Avenue, NCSB 11C-1114, Toronto, ON, Canada M5G 2N2

⁴ Gender and Knowledge Production in the Medical, Technical and Natural Sciences, Tema Genus, Linköping University, 58183 Linköping, Sweden

⁵ Divisions of Cardiology and Transplant, University Health Network, 585 University Avenue, NCSB 11-1203, Toronto, ON, Canada M5G 2N2

Correspondence should be addressed to Oliver Mauthner, oliver.mauthner@utoronto.ca

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Preparation for heart transplant commonly includes booklets, instructional videos, personalized teaching sessions, and mentorship. This paper explores heart transplant recipients' thoughts on their preparation and support through the transplant process. Twenty-five interviews were audio-/videotaped capturing voice and body language and transcribed verbatim. Coding addressed language, bodily gesture, volume, and tone in keeping with our visual methodology. Recipients reported that only someone who had a transplant truly understands the experience. As participants face illness and life-altering experiences, maintaining a positive attitude and hope is essential to coping well. Healthcare professionals provide ongoing care and reassurance about recipients' medical status. Mentors, family members, and close friends play vital roles in supporting recipients. Participants reported that only heart transplant recipients understood the experience, the hope, and ultimately the suffering associated with living with another person's heart. Attention needs to be focused not solely on the use of teaching modalities, but also on the development of innovative support networks. This will promote patient and caregiver engagement in self-management. Enhancing clinicians' knowledge of the existential aspects of transplantation will provide them with a nuanced understanding of the patients' experience, which will ultimately enhance their ability to better prepare and support patients and their caregivers.

1. Introduction

With heart transplantation comes well-documented medical and psychosocial challenges [1, 2]. Healthcare professionals are dedicated to educating and supporting transplant recipients and their families throughout this potentially difficult trajectory in order to promote engagement in self-management. Recipients are commonly prepared and supported during their transplant through a variety of modalities which include booklets, instructional videos, personalized teaching sessions, and peer mentorship. To better

understand their needs, we asked patients participating in this research study to reflect on their experience of being a transplant recipient. This paper focuses on participants' experiences and their perspectives on how to prepare and support recipients through the transplant process, which is one component of a larger study [3]. Our interdisciplinary team employed a visual methodology which allowed us to interpret body gesture and spoken words with the understanding that images and words form a set of different representations highlighting emotions and experiences [4]. Such methodology is useful as it provides an innovative

framework to engage with the complexity of transplantation [5].

2. Background

Patient and graft survival, transplant outcomes, and side effects [1], as well as the ethics of organ transplantation [6–10], have been extensively studied and will not be addressed in detail here. The average life expectancy after cardiac transplantation is 10 years with a conditional life expectancy of 13 years based on survival to year one [1]. A large number of qualitative studies show improvement in quality of life (QoL), but poor return to work (approximately 45%), as well as high general anxiety and distress among heart transplant recipients [1–3, 11, 12]. Dew and DiMartini's [13] review incorporating nearly 150 studies confirms that “depressive and anxiety-related disorders and associated distress are common post-transplant” and that such symptoms are not confined to the initial stages of recovery, but might appear or be exacerbated at any time” [page S51]. One longitudinal QoL study followed 156 patients over a four-year period post-transplant using the depression and anxiety subscales of the Symptom Checklist 90 [2]. Twenty-one percent experienced “high, clinically significant distress at all times” [2, page 1215]. Another 12% showed “high distress over several years with low distress only at final assessment,” whereas the remaining participants experienced low or fluctuating levels of distress for the duration of the study [2, page 1215]. Approximately one-third of heart recipients, therefore, were found to experience substantial, sustained distress. A multisite study investigating QoL in 555 individuals at 5–10 years post-heart-transplant found that depression accounted for the variance both in overall QoL and in health/functioning QoL [14].

In the transplantation literature, “distress” refers to psychiatric diagnoses such as depression, anxiety, and psychosis [15–22]. Psychoanalytic studies of recipients' adjustment to an organ graft have identified common responses and coping mechanisms, such as overpowering feelings of gratitude to the donor family, guilt over the donor's death, denial, and mourning of their own lost organ [23–32]. Research conducted at a major transplant center in Canada [3] with adult transplant recipients using qualitative research methods demonstrated that 88% of heart transplant patients experience pervasive post-transplant distress. Spaderna et al. [33] suggested that “social isolation, especially when combined with depression scores in the clinical range, may be important for the prognosis of heart transplant candidates” [page 252]. The authors reported that patients who died or had worsening clinical outcomes had small social networks [33]. A qualitative investigation by Kaba et al. [34] explored coping strategies of individuals following heart transplantation. Recipients adopted various forms of coping strategies, but frequently were searching for better ways to cope. Kaba et al. [34] highlighted the need for additional information for patients that outlines potential concerns post-transplant and strategies to address them.

Challenges are not limited to post-transplant experiences. Kop [35] highlighted that while waiting for a heart

transplant, candidates experience a high level of psychological distress related to the potential unavailability of a donor heart and the life-threatening nature of heart failure. The value of psychological interventions in supporting candidates in maintaining positive coping mechanisms and a healthy lifestyle was identified by Kop [35], Spaderna et al. [33], and Zipfel et al. [36]. It is important to involve family and/or significant others in candidates' daily care, because they are at risk for social isolation and their emotional well-being impacts their disease trajectory following a heart transplant [35].

In a study conducted by Haugh and Sayler [37], the team reported that maintaining respect and dignity, being sensitive to family, sharing information, facilitating coping, and doing the “extra little things,” were helpful in supporting candidates who experience uncertainty while waiting for a donor heart. An investigation by Yorke and Cameron-Traub [38] provides an in-depth description of patients' perceptions of care from nursing staff while on a heart and lung transplant waiting list. The author of this investigation highlights that nursing staff are central to the care of patients waiting for a heart transplant, because they provide information, maintain regular contact, provide familiarity, and have a positive attitude and compassion [38, page 82].

Prior to discussing the study's methods, we outline the preparation potential transplant recipients currently undergo. At the Canadian academic teaching hospital where the research was conducted, patients being listed for heart transplant are prepared for the process in a variety of ways. The first conversation about heart transplantation occurs with a cardiologist. A nurse practitioner meets with them to provide information about what to expect while waiting for, and life after, transplant. Patients are also provided with a large educational manual and a videotape that explains the biomedical aspects of the transplant in lay terms. They then meet with a social worker to discuss medication regimens, their social support network, employment, insurance, and available financial supports. Each potential recipient is offered a transplant mentor to provide support outside the program although not all choose to have one [39]. While there is a formal process to become a mentor, how the relationship unfolds and what it provides each participant are left entirely up to the patient and the mentor. There is no predetermined structure to the mentor/mentee relationship and having a mentor is not a requirement for recipient listing. This preparation program has not been formally evaluated to determine which of these patient education modalities are most effective for individuals awaiting heart transplants.

3. Methods

An interdisciplinary team, composed of two advanced practice nurses, a cardiologist, a social worker, a sociologist, a psychiatrist, and a philosopher, engaged in a qualitative research study. The study is descriptive and exploratory. As per visual methodology, interviews of heart transplant recipients were digitally audio and video recorded [3]. Our visual methodology is oriented to the work of existential

phenomenologist Merleau-Ponty [40, 41]. Like Kvigne et al. [42], we begin from the basis that existential phenomenology is not a research method. Rather, it is an orientation and sensitivity that both text and body language are central to understanding and analysis [42]. This means that we are not situating our study in the phenomenological tradition. Visual methodology is a distinct body of research in the field of sociology that is concerned with ways in which bodily conduct and talk are both important characteristics in social interaction [4]. The assumption is that images and words form a set of different representations highlighting emotions and experiences [4]. In our research, this implies incorporating an analytic approach that makes meaningful links between various experiences, visual data, and other objects. These two forms of media represent different types of knowledge that might be understood in relation to one another [4].

Members of our unique interdisciplinary research team have extensive formal training in conducting qualitative research. We bring together professors, scholars, and senior scientists in both the field of medicine and social sciences who all bring unique expertise and contributions to this research project. Informed by the work of Christian Heath and Sarah Pink who are both well known for their use of visual methodology, our team designed our unique visual methodology. We conducted pilot interviews to test our methodology, specifically our analysis process. We have published a number of papers that demonstrate how we have used video in concert with in-depth interviewing and field notes [3, 43, 44].

The study was approved by the Research Ethics Board (no. 07-0822-BE) and took place in a heart transplant program of a large metropolitan hospital in the southern portion of an eastern province in Canada. All individuals who met inclusion criteria were consecutively approached by a transplant nurse not affiliated with the study. This was done so that potential study participants had the opportunity to decline to take part in the study and not feel obligated to the investigators. When a potential participant showed interest in the study, a research associate discussed the study in detail and obtained informed consent. Thirty-six patients were approached, 6 declined to participate, and 3 did not follow through after they signed the consent. Sample size was in keeping with similar qualitative research studies and recruitment was stopped when we reached theoretical saturation.

Each patient provided written, informed consent prior to participation. The study included 27 post heart transplant patients, 2 videos were technically compromised (audio recording failure) which yielded 25 analyzable videos (70% men, mean age 53 yrs (± 13.8), range 18–72; mean time since transplant 4.1 yrs (± 2.4); 20 White, 2 Black, 5 South Asian). Participants were at least 18 years old, 1–10 years post-transplant, English speaking, and medically stable. Regardless of the time elapsed since transplantation, anecdotal and clinical involvement with transplant recipients tells us that they are able to communicate their experiences with immediacy and clarity. We accept as true that memory is a process, and as such, all participant responses reflect

their embodied experiences and enriched and informed our findings accordingly.

Individuals were given a choice of where their interview would take place. All were conducted in nonclinical settings, mostly in their homes ($n = 19$). A few chose hospital based conference or “sitting” rooms that were distinct from the clinic area ($n = 8$). Each interview was audio and videotaped to capture voice and body language concurrently. All participants received instructions on how to switch off the recording equipment at any time. The camera was purposely visible and static to film the embodied interaction of the interviewer and participant, a practice consistent with standard contemporary visual methods [45].

The use of a video camera in research has been widely debated [46–48]. Some argued that having a camera present has negligible or no impact on participants [49–51]. Researchers have also suggested that video methods are valid only if used secretly or in triangulation with other methods which reduce “contamination” of the data such as respondent validation [6, 8, 19–22]. Yet given our phenomenological orientation, we argue that these positions are not only ontologically and epistemologically incompatible with our process, but also “run the risk of blinding themselves to the advantages of videoing as a method” [25, page 1154]. As visual methodologists, we espouse that we cannot observe the world without being present in it; hence, we believe that the use of camera was not neutral in the interview, but rather was a fundamental part of knowledge production [3]. During the interviews, the completely exposed camera became inconspicuous for both the interviewer and the participant. No participants chose to interrupt or stop the video recording at any time.

The interviews were conducted individually by one of two advanced practice nurses with extensive training in qualitative research and no involvement in the study participants’ clinical care, on average four and a half weeks after recruitment. Approximately 30 minutes was spent prior to each interview answering questions about the research, establishing rapport, and building trust with the participants [52]. Participants were informed that they could refuse to answer any question, stop the interview at any point, or request erasure of anything they said. Following standard procedures in semistructured qualitative studies, the interviewer asked participants open-ended questions and provided opportunities for them to raise their own concerns. For example, participants were asked both “How would you prepare someone for transplant?” and “How would you support someone after transplant?” Techniques such as nodding, allowing silences, and using phrases such as “would you feel comfortable telling me more about that?” were utilized when necessary [53]. Interviews took 30–90 minutes. Following every interview, the researcher compiled detailed field notes of observations. Coding conventions established by Poland and Pederson [54, 55], such as noting laughter, silences, and pauses in addition to dialogue, were used to professionally transcribe audio files verbatim. Digital video files, transcripts and field notes, were imported into the NVivo8 qualitative research software program.

All interviews were viewed in their entirety by the research team. The team met as a group together in the same room throughout the analysis process. The video and transcripts were analyzed simultaneously and in an iterative process. Coding was informed by the work of visual methodologists Pink [4, 56] and Heath [45, 57], using NVivo8 to organize the data. The first phase of data analysis started with a transcript and videotape review in which they were simultaneously time logged, and “key moments” were noted [4]. Key moments included particular statements in transcripts and videotaped embodied responses such as “expressive gestures” [57, 58] that located “areas of difficulty” on/in the body (e.g., hands on heart; pointing to the heart) [57, 58], “expressive artifacts” (e.g., open necked shirts showing surgical scars), and “by the way syndrome”, that is, the gestures and comments close to the end of interviews that (re)asserted the “significance or seriousness of a particular symptom/feeling” [57, 58]. Finally, “incongruities” between participants’ words and gestures were noted [57, 58]. These include but are not limited to “upgrades,” which represent speaking positively even when body comportment indicated distress (i.e., inability to maintain eye contact; crying; intense fidgeting), or “downgrades” when comportment appeared nondistressed (i.e., calm tone of voice; relaxed posture) even though words revealed the opposite [57, 58].

In the next phase of data analysis, all audio visual data were collectively re-reviewed. Broad themes were developed by the team from transcript quotes and audio visual footage and where tagged to key moments. These themes were defined, discussed, debated, and agreed on by the team before being collapsed into analytic categories. The team then collapsed these analytic categories into a final set of themes which addressed the research question [3]. To meet the highest standards of methodological rigor, an audit trail was maintained (specific record of methodological and data coding decisions). The flexible storage, cross-indexing, and quick retrieval features of NVivo8 made it easy to search for negative instances and universal findings [59]. Attention was paid to data inconsistent with overall findings, and coding was discussed with all members of the team. Issues not resolved through consensus led to discussion and further analysis.

4. Results

In reporting data in visual methods research, we are unable to use video footage to show our findings; hence in this paper we rely solely on words to discuss results. We have therefore adopted a very descriptive writing style to compensate for what cannot be seen. The aforementioned analysis processes led to the identification of several themes. The most common theme was recipients’ sense of not being fully understood. Participants talked about that only someone who has gone through this process truly understands the complexity of their experiences. Other themes included the need to maintain hope, where a positive attitude was seen as essential in order to move forward. Participants reported that ongoing close connections with healthcare professionals (HCPs) provided reassurance about their ongoing medical care. The

presence of family and friends was also seen as essential, as was their help in managing day-to-day activities. Mentorship programs provided a different and unique form of support between individuals who may share an understanding or experience. The mentor-mentee relationship is often developed between an individual who is awaiting transplant and a transplant recipient.

4.1. Not Understood. Fourteen patients (56%) commented that only heart transplant recipients truly understood the experiences they were going through. Hence, transplant recipients were most able to prepare them for transplantation and support them afterwards. Participants expressed that living through heart transplantation cannot be compared to any other medical condition. They reported it was a very emotional, distressing, and physically demanding. To this end, all recipients felt their transplant experience was unique.

A thirty-year-old woman, who was interviewed in a room close to the heart transplant clinic area, slouched down in her chair while she said “... I do not like to tell people unless they’ve been through something similar, because the truth is that you cannot really understand unless you’ve been through the same thing... (PTx13).” She seemed to have reconciled herself to the idea that other people just would not understand, and she had told few people about her ordeal. A fifty-six-year-old man, who was interviewed in his home, sat crossed legged on a couch with closed posture. In a very monotone voice he spoke about what he would say to a potential recipient as follows: “... look, if you are really in a bad way, here is my phone number, here is my email... I know exactly what you are going through, I know how bad it gets, you cannot surprise me, just phone... (PTx12).” He communicated this in a voice devoid of inflection and as if he had rehearsed this message. Another man in his early thirties, sitting at his kitchen table, used expressive gesture and voice said “... I think education is important but sometimes you also have to live through it to understand it (PTx21).” His message had a sense of urgency, emphasizing the difficulties associated with not being understood. A man in his late fifties sitting at his kitchen table stated “You know, you guys [transplant team] think you know what we went through, but you do not (PTx10).” The difficulty for him in communicating this was apparent in his low and flat tone of voice as he nervously twirled his fingers and avoided eye contact.

4.2. Maintaining Hope. Maintaining their positive attitude after transplant was reportedly very important for 13 (52%) of the recipients. Their statements included endorsements of not being told about potential transplant-related complications or personal struggles and receiving only encouraging words. A fifty-four-year-old woman, who was interviewed at a large table in a dimly lit kitchen, said with a very worried look on her face “Well, you have to encourage this person... never tell them... Oh, my God, you know, tomorrow you are going to be worse, never say that to the person who went through a nightmare... never discourage people (PTx15).” As the inflection in her voice rose, in an effort to make her point clear, she wrapped her arms around her body,

as if comforting herself while sharing her difficult story. Nervously giggling, a man, who had spoken previously in his interview of the emotional difficulty of going through a heart transplant, said that if he were to speak to another patient, he would say “Do not worry about it, everything is going to be fine... I would tell him that he is going to feel good after. He is going to feel better than before. . . (PTx17).” As he completed his statement, he leaned forward with open arms to enforce that although his experience was difficult, he would only share positive outcomes with other potential recipient.

4.3. Ties to the Team. Thirteen (52%) recipients commented that HCPs had provided the needed reassurance about their ongoing medical status and continuity between the transplant clinic and their home. A fifty-six-year-old man who was seven years post-transplant stated “my support system, I would have to say, are the transplant nurse coordinators because if ever there is a problem I could just call them, and they do phone back. . . I just feel very protected and well taken care of. . . whenever I had questions, all I needed to do was call, and they were answered (PTx12).” At this point in his interview, the participant relaxed his posture and seemed to speak more freely about his experience. Another male participant stated that “. . . they [HCP] are there if you need them, but like I say, first couple of years you really depend on them, you feel so much better going there [hospital]. . . . The transplant team is really extraordinary. I do not know how they do it. . . (PTx10).” He made this statement with a clear assertive voice and repeated it more than once. Another young man reported “My support system, I would have to say it’s [Advanced Practice Nurses’ names], because if ever there is a problem, you know, I can just call them. . . I think in the whole that I just feel very, uhm, protected and well taken care off from there [hospital], so whenever I have problems. . . questions, all I needed to do was call. . . (PTx22).” He represented this in a very matter of fact fashion, as if the answer was obvious.

4.4. Family and Friends. Family members and close friends were reported by 5 (20%) recipients to have been an important part of their lives throughout the transplant experience. Sitting very composed with crossed legs, a male interviewee flatly said “[wife’s name] was there all the time, right with me, and there were a couple of really good friends who just made sure I was OK. . . (PTx12).” He spoke as if his answers had been scripted, using a very monotonous tone of voice and a very controlled body posture. A physically fit looking man who sat at a table stated “I think they [recipients] need to have somebody around because the days are long. . . they need to have somebody around that can, you know, they can gab with and hang out with, so you do not have all that time to think (PTx14).” A woman, sitting in a large, well-appointed living room stated “There are lots of people in my life who have been really great trying to help me out. But mostly my husband, he has been a saint, a saint. . . I honestly do not know how somebody could get through it alone. If I had not had my husband, I would not have made it.

You just. . . you cannot. It is so hard to do alone (PTx24).” She delivered her message with a lot of emphasis and certainty; there was conviction in her voice. She continued by saying “. . . you just have to be there for them [transplant recipients]. I would imagine that driving people around would be all part of it, and being with them. Some of it is you need them there to do stuff for you, another is to . . . commiserate with you (PTx24).”

4.5. Mentorship. The transplant program offers every patient the opportunity to connect with a mentor, who is a transplant recipient. When participants were asked how to best support transplant recipients, 10 (40%) spontaneously spoke of this mentorship program. Six of those 10 recipients reported having elected to be mentored and described it as a supportive experience. The 4 participants, who had declined having a mentor, retrospectively thought being a mentee would have been beneficial. A frail looking older married woman, sitting at her kitchen table, said how helpful it had been “. . . because you always wonder what it is going to be like after the transplant, and seeing someone by your bedside that has already had a heart transplant. . . just saying everything is going to be fine. . . (PTx9).” As she said the words “everything is going to be fine,” her body changed from being slouched forward with arms crossed and she became more engaged by using expressive gestures and increasing the tone and inflection of her voice. A retired man, who reported during his interview that the support of mentors was vital in his recovery, nervously chuckled as he said “I did hear a lot of people saying that they did not have much support as far as mentors. . . it’s a big thing [transplant], it’s too bad. . . I think the mentor thing is really good (PTx10).” Another man appeared content and comfortable sitting in his living room stated, “They set you up with a buddy system. . . We met up and had a chat. . . its nice to see somebody that’s had a transplant. . . I do not think anybody said too much negative, the only thing is I think they all, after a few years, forget the sort of bit of trauma you go through. . . (PTx11).” He leaned comfortably back in his chair, crossing his hands in his lap.

5. Discussion

Many participants speak about the difficulty of living with a transplanted heart. They stressed that most “others” do not understand what recipients go through and that only someone who has a heart transplant truly understands the experience. Similar findings have been reported by Sadala and Stolf [60]. Our effort to uncover what “we do not understand” led us to further explore why transplant recipients think that only someone who has lived through the transplant experience understands them. Conventional research methods have not been comprehensive or sensitive enough to understand the multifaceted aspect of patient experience because the focus has been on the written or spoken word. Such methods ask participants to speak or enumerate their experience of heart transplantation but fail to illuminate what cannot be spoken. Hence, the unspoken

ultimately remains hidden from the researcher. As described by visual methodologist Heath [58], suffering can be seen in the body through expressive gestures and tone of voice. The use of visual methods enables researchers to interpret the expressive body, making visible what would otherwise remain hidden. Embodied suffering is revealed through visual methods. Its use in the study reported here enabled us to innovatively engage with transplant recipients' unique experiences and gain new insights into their ongoing suffering.

To this end, the interviews captured the very body showing everything the mind suffers: crying, moaning, lacking affect, dropping their tone of voice, speaking monotonously, stooped shoulders, head dropped forward, avoiding eye contact and legs crossed. In this paper, the notion of suffering captures participants' affective experience of sadness or unpleasantness. Heath [58, page 603] reports that "through gesture and bodily conduct, patients transpose inner suffering, their personal subjective experience of their complaint, to the body's surface and particular parts and areas of their physic". As described in our findings, the interviewees' bodily comportment characterizes the difficulty of receiving a heart transplant allowing the research team to witness their suffering. In order to better support our recipients, we turned to the work of Frank [61, page 355] to gain further insight about suffering.

Suffering is the unspeakable, as opposed to what can be spoken; it is what remains concealed, impossible to reveal; it remains in darkness, eluding illumination; and it is dread, beyond what is tangible even if hurtful. Suffering is loss, present or anticipated, and loss is another instance of nothing, and absence. ... Suffering resists definition because it is the reality of what is not.

If suffering is "unspeakable," it explicates why more than half of the study participants felt only someone who has walked, lived, and suffered in their shoes could understand their plight [61]. It also demonstrates how the experience of post-transplant suffering might remain hidden from professionals, defying language and more standard research methods. Taking this analysis further, it is possible to look at a wound as a metaphor for suffering [61]. A physician might look at the wound in diagnostic/clinical contexts (i.e., healing, infection), whereas for the patient, the wound is something experienced, felt, seen, and smelled. Health care practitioners look at heart transplantation through a clinical/diagnostic lens. Recipients are assessed and measured: weight, blood pressure, and body temperature are recorded, blood work is reviewed, and biopsies are performed and examined—all to ensure that the transplanted organ remains healthy and that the individual's body is not rejecting the heart. Healthcare practitioners also value recipients' psychological well-being and the importance of quality of life. Yet recipients continue to report anecdotally, and in the study reported here, that most clinicians do not understand them, and yet they play an essential role in providing support related to the medical management. There seems to be a divide between bodies that receive transplants and

transplant recipients' lived experience of these bodies. Given that the recipients' lived experiences are private, personal, and often indescribable, they are not accessible to HCPs. This disconnect cannot be overcome solely by asking recipients what their experience of living with a transplanted heart is like. As highlighted by Frank [61], when patients are asked to talk about difficult experiences such as their transplantation, they are unable to fully articulate their experience and tend to express it through particular complaints and concerns. What remains concealed is their suffering. Frank [61] best describes this when he says "suffering is expressed in myth as the wound that does not kill but cannot be healed" [page 355]. It follows that until patients' suffering is understood, this existential wound cannot heal. Each recipients' suffering is rooted in their embodied experience, and as long as HCPs do not engage with their embodied lived distress, a disconnect will continue. Our intent was to find ways to enhance clinicians' knowledge of and ability to provide appropriate support. When asked how to best do this, participants reported that providing encouragement and not focusing on potential negative disease sequelae were very important to maintain hope.

Hope was described as an essential component in dealing well with illness and life-altering experiences. Wiles et al. [62] performed a narrative literature review about hope, expectations, and recovery from illness. They highlighted that it is essential to understand the function of hope when dealing with illness and the recovery process as it "provides a coping mechanism in the face of what people may experience as the otherwise intolerable impacts of a health crisis, and maybe a common adaptive response... [62, page 569]." They describe hope as having two components: hope as an "expectation" and hope as a "want." Within the context of the research presented here, hope as an expectation in heart transplant recipients includes hoping that specific symptoms or events will not occur during one's disease trajectory. Alternately, hope as a want is less likely to be realized. A heart transplant recipient might hope to meet the donor family or return to his/her old "self." To this end, our research team acknowledges that HCPs should be aware of this nuanced understanding of hope to better support the patient, because it is conceivable that false hope could adversely affect recovery.

Participants identified three major sources of support: their transplant team, family and friends, and transplant mentors. These findings are in keeping with reports from Sadala and Stolf [60]. When conceptualizing what participants discussed about support, we draw on the work of King et al. [63] who studied social support processes of individuals with chronic conditions. King et al. [63] described distinct categories of psychological support, including "instrumental support" (allowing participants to achieve self-efficacy through direction and planning of approaches) and "emotional support" (being valued and accepted provides participants the sense of "being believed in") [page 915]. These themes are consistent with participants' accounts in our study and will guide the following discussion.

Participants reported that health care professionals provided "instrumental support" to transplant recipients

through ongoing assessment of health status and guidance in their self-management of care. In doing such the HCPs also provided emotional support to individuals. Participants were able to review their concerns with transplant professionals during clinic visits as well as through a sophisticated patient management telephone system, providing them not only with access to resources, but also with ongoing reinforcement to be able to manage their own care. This type of support provided transplant recipients with strategies to ultimately enhance their competence taking on the onerous tasks of self-management. Such tasks include managing their medications, medical challenges, and adapting to their altered life with a transplanted organ.

For some transplant recipients, the mentor/mentee relationship has continued throughout the transplant trajectory. The ability for transplant recipients to connect with individuals, who have experienced a similar process, provides an opportunity for the provision of “emotional support.” The mentor/mentee relationship offers a unique connection between transplant recipients that creates a sense of belonging. King et al. [63] describe that when “emotional support” is provided, people feel accepted and trusted, promoting a sense of “being believed in.” Hence, mentors who have been through a similar experience, allow transplant recipients to feel understood. Mentor/mentee relationships afford an additional benefit, in that providing and receiving support can be mutually beneficial [64]. In supporting another recipient, the mentor gains a sense of meaning and satisfaction, which in turn might improve adaptation to their own illness.

The presence and availability of family and friends provided great comfort to some transplant recipients. Assistance with day to day responsibilities and having others around even if they are “just being there” are both sources of comfort and support [65]. Study participants talked about receiving support with household chores and help with tracking medications and medical appointments. Having a family member or a friend present during clinic visits and invasive procedures similarly provided support to transplant recipients. It is important for HCPs to recognize the significance and complexity of the role that family and friends might play during the heart transplant recipient’s life trajectory.

6. Study Limitations

Participants, although ethnically and socioeconomically diverse, were all recruited from a single academic health care setting. They were recruited consecutively as they attended routine follow-up clinics to minimize bias. Our study population represents sex, ethnic, and social demographic groups that are comparable to our larger urban transplant program population. Both interviewers are researchers with this study, actively participating in all aspects of the research process, and are the main authors of this manuscript. Although all study participants were asked the same questions, in keeping with conventions of semistructured interviews, the discourse of the interview was not directed by the interviewer, allowing the conversation to evolve spontaneously. Consequently, not

all participants spoke of the same topics, limiting the ability to draw conclusions about participants who did not report on certain themes.

7. Conclusion

Participants felt that few people understood what they were going through and that only someone who has had a heart transplant truly understood the experience, the suffering, the hope, and a second chance at life. If Frank is correct, because of the unspeakable nature of suffering, key issues of the transplant experience remain hidden from the HCP and most researchers. Visual methods provide a portal to more comprehensively engage with the notion of suffering. They might allow researchers and ultimately HCPs to understand and hence acknowledge heart transplant recipients concerns, thereby giving their experiences legitimacy. Also, knowledge of the existential aspects of organ transplantation will provide HCPs with a nuanced understanding of the patients’ transplant experience. This will allow them to better prepare and support patients through the transplant process, and ultimately promote patient and caregiver self-management.

In our research, we found that despite others inability to truly understand the transplant experience, ongoing relationships with family, friends, and healthcare providers were none-the-less fundamental in the provision of continuous support. In an effort to build stronger support networks, we also need to look at innovative ways to educate individuals who will be providing support for transplant recipients. Written teaching materials and instructional videos should not be the exclusive recipient preparation modalities because interpersonal relationships and interactions, including the mentorship program, were considered more helpful and supportive. Strong efficacious mentorship programs need to be developed and evaluated, recipient support networks need to be encouraged, clinicians’ knowledge of the existential aspects of organ transplantation need to be enhanced.

Conflict of Interests

The authors of this paper have no conflict of interests to declare.

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