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Exploring learning processes associated with a cancer pain self-management intervention in patients and family caregivers: A mixed methods study

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ABSTRACT

Aim: Explore learning processes associated with a psychoeducational pain selfmanagement intervention. Background: Self-management of cancer pain is challenging for patients and their family caregivers (FCs). While psychoeducational interventions can support them to handle these tasks, it remains unclear how learning processes are hampered or facilitated.

Methods: A convergent parallel mixed methods design with qualitative data collection embedded in a randomized controlled trial (RCT) was used. Outpatients with cancer and FCs were recruited from three Swiss university hospitals. The six-week intervention consisted of education, skills building, and nurse coaching. Quantitative data on pain management knowledge and self-efficacy were analyzed using multilevel models. Patients and FCs were interviewed post-RCT regarding their learning experiences. Qualitative data analysis was guided by interpretive description. Finally, quantitative and qualitative data were integrated using case level comparisons and a meta-matrix.

Results: Twenty-one patients and seven FCs completed this study. The group-by-time effect showed increases in knowledge (p=0.035) and self-efficacy (p=0.007). Patients' and FCs' learning through experience was supported by an intervention nurse, who was perceived as competent and trustworthy. After the study, most intervention group participants felt more confident to implement pain self-management. Finally, data integration showed that declining health hampered some patients' pain self-management.

Conclusions: Competent and trustworthy nurses can support patients' and FCs' pain self-management by providing individualized interventions. Using a diary, jointly reflecting on the documented experiences, and addressing knowledge deficits and misconceptions through the use of academic detailing can facilitate patients' and FCs' learning of critical skills.

1. Introduction

Despite effective treatments, over 40% of patients with cancer report unrelieved pain (Breivik et al., 2009). With the home becoming the primary setting for cancer care (Rubin et al., 2015), patients and their

family caregivers (FCs), defined as relatives, partners, friends, or neighbors who provide care to patients (Shajan & Snell, 2019), play a central role in the implementation of cancer pain self-management (Ferrell, 2019). One of the foci of effective pain management is the use of analgesic medications (World Health Organization [WHO],

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2018). Therefore, cancer pain self-management involves learning skills such as obtaining prescribed medications; taking them at the right time and in the right way; as well as reacting appropriately if pain is not relieved or side effects occur (Schumacher et al., 2014). However, patient-related barriers hamper the implementation of effective self-management strategies (Al-Ghabeesh et al., 2020; Scarborough & Smith, 2018): Concerns about addiction, fear of side effects, miscommunication with physicians, and erroneous beliefs about analgesics can impede self-management. FCs often endorse these same barriers (Konstantis & Exiara, 2018).

According to recent meta-analyses (Ferrell, 2019; Ferrell & Wittenberg, 2017; Lee et al., 2014; Northouse et al., 2010; Oldenmenger et al., 2018; Sheinfeld Gorin et al., 2012), the provision of a psychoeducational intervention can moderately reduce pain and improve knowledge regarding cancer pain management. In addition, it can decrease fears, as well as enhance mood, self-efficacy, and communication skills in FCs. However, studies included in these reviews varied greatly in terms of the types and duration of the interventions. While knowledge of cancer pain management improved in patients and FCs, it is not entirely clear what might facilitate or hamper the learning processes leading to these improvements.

Bandura's Social Cognitive Learning Theory (SCLT) provides a theoretical framework to understand learning processes. Learning is a cognitive and behavioral process of modifying existing or gaining new knowledge, skills, values, or preferences that takes place in a social context. Interactions among personal/cognitive, behavioral, and environmental factors can influence learning processes (Bandura, 2001). Learning occurs through observations, regulated by four steps: attention, retention, reproduction, and motivation. Moreover, learning processes are influenced by pre-existing knowledge and how learners interpret previous experiences. As part of the SCLT, Bandura introduced the concept of self-efficacy expectations, defined as the confidence in one's ability to perform behaviors necessary to achieve a specific outcome (Bandura, 1989). Past experiences are the most important source of self-efficacy. Furthermore, vicarious experiences, verbal persuasion, feedback, and goal setting can influence self-efficacy expectations, learning processes, and thinking patterns (Bandura, 2013).

Based on Bandura's SCLT, a psychoeducational intervention, the PRO-SELF© Pain Control Program (PCP), was developed to support pain self-management. Tested in a randomized controlled trial (RCT), significant decreases in pain and increases in knowledge were found in a U. S. sample of 174 outpatients with cancer and their FCs (Miaskowski et al., 2004; West et al., 2003). Later, two doses of the intervention were compared using the PRO-SELF© Plus PCP (Miaskowski & Schumacher,

2006). In a pilot RCT, this extended version was culturally adapted, translated into German, and tested for feasibility (Koller et al., 2013). Then, this adapted German version was refined and tested within a Swiss, multi-center study (Valenta et al., 2018). This mixed methods study provided an opportunity to explore learning processes in outpatients with cancer and their FCs. To increase our understanding of these processes, the purposes of this study were to: 1) evaluate the efficacy of the adapted German PRO-SELF© Plus PCP in increasing patients' knowledge of cancer pain management and their self-efficacy; 2) explore patients' and FCs' learning processes and what facilitated or hampered learning; and 3) integrate quantitative and qualitative data to better understand changes in patients' and FCs' knowledge and use of pain self-management strategies.

2. Materials and methods

A convergent, parallel mixed methods approach was used (Creswell & Clark, 2017). Quantitative and qualitative data were analyzed separately and then integrated to increase our understanding of participants' learning processes (Fig. 1).

2.1. Sample and settings

Patients and FCs were recruited by research assistants (RAs) from oncology outpatient clinics at three Swiss university hospitals. Patients were included if they: had experienced any type of cancer pain rated as ≥ 3 on a 0–10 numeric rating scale (NRS) over the past week; had an estimated life expectancy of >6 months; were aged ≥ 18 years; were able to understand, read, and write German; and had access to a telephone. Patients were excluded if they: had cognitive dysfunction or hearing impairment, experienced solely neuropathic pain, or were hospitalized for >2 weeks during the study. If FCs were involved in the patient's pain management, they were invited to participate. Written informed consent was obtained from all participants. Patients were stratified by site and randomized 1:1 into either the intervention (IG) or control (CG) group. The study was registered and approved by all responsible ethics committees (ClinicalTrials.gov: NCT02713919).

2.2. Study procedures

Both the IG and the CG participated in the study for 7 weeks and received home visits at enrollment (week 0), week 1, and week 6. All patients completed pain management diaries and questionnaires; FCs completed questionnaires. Specially-educated nurses with a Master's

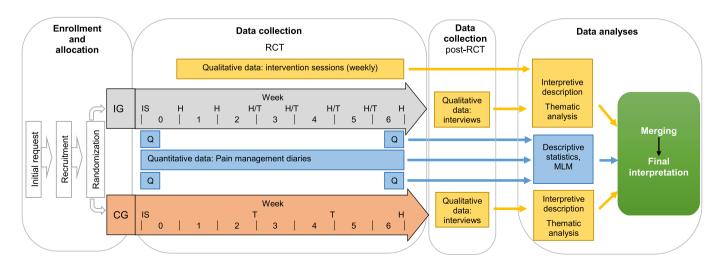


Fig. 1. Mixed methods convergent study design. *Note*. Abbreviations: CG = control group; MLM = multilevel linear models; H = home visit; IS = initial session; IG = intervention group; Q = questionnaire; RCT = randomized controlled trial; T = telephone call.

degree in Nursing provided the intervention. IG data were collected by the intervention nurses (INs). CG data were collected by RAs. A subgroup of IG and CG participants were interviewed post-RCT.

2.2.1. The intervention

The adapted German-version PRO-SELF© Plus PCP is based on three key components: nurse coaching, skills building, and provision of information through academic detailing (O'Brien et al., 2007; Soumerai & Avorn, 1990). The specific type, content, and duration of the intervention sessions are outlined in Table 1. To ensure the fidelity of the intervention, all of the intervention sessions were audio-recorded. The primary investigator reviewed these recordings for any deviations from the study protocol. Any deviations were discussed with the INs and subsequent intervention sessions were reviewed.

2.2.2. Usual care

CG participants received usual care regarding pain management. Their physicians assessed pain and prescribed pain medications as per commonly acknowledged standards. No specific counseling was provided. Participants who asked questions about pain or side effects were encouraged to contact their physicians.

2.3. Variables and measurement

The Patient Pain Questionnaire (PPQ) and the Family Pain Questionnaire (FPQ) consist of nine items that measured knowledge of pain management using a 0 (disagree) to 10 (agree) NRS (Ferrell et al., 1993). Higher scores indicate more knowledge. German versions of the PPQ/FPQ were used (Koller et al., 2013). The 15-item Self-Efficacy Questionnaire (SEQ) measured the patient's perceived ability to manage aspects of pain using a 10 (very uncertain) to 100 (very certain) NRS (Anderson et al., 1995). Both groups of patients completed, on a daily basis, a pain management diary to assess average and worst pain for the previous 24 h using a 0 (no pain) to 10 (worst imaginable pain) NRS (Radbruch et al., 1999).

Table 1
Overview of type, duration and content of initial and intervention sessions.

2.4. Qualitative data collection

The qualitative component was guided by interpretive description (Thorne, 2016). The audio-recorded intervention sessions and post-RCT interviews provided the qualitative data. From the intervention sessions, all of the educational content on self-management of cancer pain and side effects were transcribed. A total of 77 transcripts were available from initial sessions, home visits, and telephone calls.

Post-RCT interviews were conducted with IG and CG participants. Initially, purposive sampling was planned. However, with a number of recruitment challenges, all participants who completed the study were asked to participate in the interviews. Patients and FCs were interviewed by specially educated nurses, the study coordinator, or the principal investigator. Following an interview guide, the interviewers asked openended questions to explore participants' experiences with pain and side effect self-management, study participation, what they had learned from the intervention, and how learning occurred. Interviews were conducted three to 28 days after completion of the RCT, audio-recorded, and transcribed.

2.5. Data analysis

Quantitative data were retrieved from the SecuTrial® database and systematically examined for out of range values and inconsistencies. Descriptive statistics and frequency distributions were calculated. An intention-to-treat analysis was applied, using a significance level of 0.05 (Gewandter et al., 2014). Multilevel models were used to determine IG/CG differences in pain management knowledge and self-efficacy from the initiation to the completion of the intervention by entering group x time interactions into the models. Quantitative data were analyzed using SPSS 24.0 (IBM Corp. Released, 2016).

Qualitative data were thematically analyzed following Braun and colleagues' six-phase iterative procedure (Braun et al., 2019). ATLAS.ti 8 was used for data management (ATLAS.ti Scientific Software Development GmbH, 2019).

Finally, quantitative and qualitative data were integrated. First, to

	Time point	Type of intervention session	Mean duration of intervention session (SD, range)	Content of intervention session (according to guideline)
Initial session	Baseline data collection Within 2 days	Home visit or appointment in the clinical setting Control telephone call	32 min (±12 min; range = 14–69 min) 3 min (±1 min; range = 2–5 min)	IN explained study content and procedures, submitted questionnaires and pain management diary Clarification of open questions
Intervention sessions	Week 0, 1 and 6 Week 2–5	Home visit Home visit or telephone call: Home visit, if one or more of the following criteria applied: Pain score > 3 on a 0-to-10 NRS Patient is dissatisfied with pain management Patient adherence with pain medication < 50%	61 min (\pm 18 min; range = 23–100 min) 60 min (\pm 16 min; range = 35–105 min)	After an initial pain assessment, the IN provided structured and tailored components of the adapted German PRO-SELF© Plus PCP Structured components IN educated patients/FCs how to document analgesics taken, to use a one-week pillbox, to monitor pain and analgesic side effects and to communicate pain situation with physicians IN addressed and discussed participants' knowledge of cancer pain management based on specific survey (PPQ/FPQ items) Participants received written information (booklet) Tailored components
		Telephone call, if criteria did not apply	21 min (\pm 10 min; range = 4–45 min)	 IN reviewed pain diary, assessed the appropriateness of the analgesic prescription and side effect management IN taught the patient/FC how to adjust their medications within the physician's prescribed dose range in response to changing pain conditions and side effects IN and participants set weekly goals and individualized symptom management plan
	Week 0–6	Reinforcing telephone call	$7 \text{ min } (\pm 3 \text{ min; range} = \\ 413 \text{ min)}$	IN scheduled additional telephone call within 48 h after a home visit or a telephone call, if major changes were made to the patient's symptom management plan.

Abbreviations: Approx. = approximately; FC = family caregiver; FPQ = Family Pain Questionnaire; IN = intervention nurse; min = minutes; NRS = numeric rating scale; PCP = Pain Control Program; PPQ = Patient Pain Questionnaire; SD = standard deviation.

further explore what hampered or facilitated participants' learning processes, qualitative data were compared and contrasted with pain intensity and self-efficacy scores as well as patient characteristics on a case-by-case level. Second, to better understand changes in the pain knowledge of IG participants, qualitative data related to pain knowledge were combined with PPQ/FPQ scores on a case-by-case and item level basis. A meta-matrix was built with qualitative and quantitative data aligned in rows (Steinmetz-Wood et al., 2019). Then, the aligned data were evaluated for recurrent patterns.

3. Results

3.1. Sample characteristics

From March 2016 until December 2018, 34 patients enrolled in and 21 completed this convergent, parallel mixed methods study. The demographic and clinical characteristics of the patients at enrollment are listed in Table 2. Nine FCs (i.e., one daughter, six wives, two husbands) participated (IG = 5; CG = 4; mean age = 58 ± 11 years). Thirteen post-RCT interviews with patients were conducted (IG = 8; CG = 5; mean age = 67 ± 12 years; 77% male). Four FCs (IG = 3, CG = 1) participated in the interviews.

3.2. Changes in PPQ and SEQ scores

While the total PPQ score increased from enrollment (5.7 \pm 1.1) until the end of the study (7.3 \pm 1.2) within the IG (p=0.008), mean scores for items #1, 2, 8, and 9 had the largest increases (Supplementary Fig. 1). Mean scores for items #3 and #4 about fears of physical and psychological addiction, respectively did not change in the IG. Comparison of changes between the IG and CG showed a significant group \times time interaction for the total PPQ score (p=0.035).

In the IG, the total SEQ score increased from enrollment (69.2 \pm 18.5) until the end of the study (79.9 \pm 17.8, p=0.011) and all individual items increased (Supplementary Fig. 2). Comparison of changes

Table 2Differences in demographic and clinical characteristics between the patients with cancer in the intervention and control groups at enrollment.

	IG (n = 17)	CG (n=9)	<i>p</i> - Value
Demographic and clinical chara	ecteristics		
Age in years, mean (SD)	66.6 (14.5)	64.1 (11.0)	0.658
Female, n (%)	6 (35.3)	4 (44.4)	0.655
Lives alone, n (%)	0 (0.0)	1 (11.1)	0.169
Married/partnered, n (%)	12 (70.6)	7 (77.8)	0.756
Employed, n (%)	1 (5.9)	1 (11.1)	1.0
Highest education, n (%)			0.524
Elementary school	7 (41.1)	1 (11.1)	
Vocational training	1 (5.9)	2 (22.2)	
Commercial school	1 (5.9)	2 (22.2)	
University degree	7 (41.1)	4 (44.4)	
Other	1 (5.9)	0 (0.0)	
Therapeutic goal palliative, n	14 (82.4)	7 (77.8)	1.0
(%)			
Cancer diagnosis, n (%)			0.455
Breast	1 (5.9)	2 (22.2)	
Prostate	3 (17.7)	2 (22.2)	
Lung	3 (17.7)	1 (11.1)	
Other	10 (58.8)	4 (44.4)	
Months since diagnosis			0.895
Mean (SD)	98.5 (71.0)	102.5 (69.2)	
Median (25/75 percentiles,	89 (42/142,	106 (32/163,	
range)	21–274)	13-207)	
Pain and symptom severity cha	racteristics	•	
Average pain, mean (SD)	4.3 (1.8)	3.7 (1.3)	0.266
Worst pain, mean (SD)	5.3 (1.9)	5.1 (2.0)	0.462

 $\it Note.$ Abbreviations: $\it CG = control$ group; $\it IG = intervention$ group; $\it SD = standard$ deviation.

between the IG and CG showed a significant group \times time interaction for the total SEQ score (p = 0.007).

3.3. Experiencing learning processes

Qualitative findings are presented as three themes related to the components of the intervention. Prior to the intervention, patients reported that they experienced uncontrollable pain and side effects. Over the study period, patients' and FCs' learned from a competent and trustworthy coach. After the study, IG participants who experienced success improved their pain self-management.

3.3.1. Experiencing uncontrollable pain and side effects

Before the intervention, many patients experienced changing and poorly controlled pain. They were reluctant to take pain medication, particularly opioids, because they feared side effects, primarily constipation, as well as addiction or over-use.

Patient: And I would never have risked taking more, because I thought that I would then be completely gaga. One never talked about that. And then, you're just constrained. Because it is said that morphine is addictive.

Some patients considered pain a bodily warning signal they should feel. Several suffered from side effects, mainly constipation. For some, pain interfered with daily activities. Others stayed at home and lost contact with friends. Watching the patients in pain hurt their FCs. They were uncertain and anxious. They considered themselves at the limits of their endurance. Tensions between suffering patients and helpless FCs were common.

FC: He does not let me tell him what to do. Yeah, that's what got me down.

Before the intervention, most patients did not have a systematic approach for pain management. The majority were prescribed ATC and PRN opioids. Several patients were receiving pregabalin and/or other analgesics. However, only a few took ATC opioids regularly and PRN opioids as needed. Many took both ATC and PRN analgesics only when they were in pain, reduced the prescribed dose, or did not take any opioids to avoid unmanageable side effects. While most had trustful relationships with their physicians, consultations were short, some patients and FCs were stressed, or their treating physicians changed unexpectedly. These patients and FCs lacked sufficient information on how to effectively manage pain and side effects.

3.3.2. Learning from a competent and trustworthy coach during the intervention

The IN conducted detailed weekly pain assessments with each IG patient that included reviewing the pain diary with the patient and FC. Of note, all of the participants completed their diaries correctly. The IN evaluated pain and side effect scores and reviewed participants' management strategies, noting whether pain and side effects were relieved. In particular, she asked patients if they had taken their prescribed ATC/PRN analgesics and laxatives. If not, she explored reasons for nonadherence. That is, starting from the patients' and FCs' understanding of their pain and side effects, the IN interpreted the diary for them, helping them to learn from their experiences. The diary helped some patients delve into, reflect upon, and make decisions about their situation. Of note, two CG participants used the diary to adapt their physical activity. However, they lacked the input from the IN to improve their pain and side effect self-management.

CG patient: Regarding pain and pain treatment nothing has actually changed. But what I have really learned: What's good for me and what's not good for me!

Based on the principles of academic detailing (O'Brien et al., 2007; Soumerai & Avorn, 1990), the IN reviewed the completed PPQ/FPQ and evaluated participants' knowledge and previous experiences with pain

management. Discussions between the patients and FCs were facilitated, especially if they disagreed. Afterwards, the IN emphasized positive views and experiences; clarified any misunderstandings and uncertainties; and provided expert information.

The individualized intervention sessions enabled the participants to independently implement pain self-management strategies and to adequately communicate changes to their physicians: The IN explained the onset, duration, and differences between ATC and PRN opioids using graphical illustrations; taught patients how to adjust the administration times for prescribed ATC opioids to their individual daily routines; and how to take PRN doses correctly. In addition, she assessed the appropriateness of the prescribed analgesics and discussed potential adjustments. If necessary, the IN wrote a script for patients to use to discuss needed changes in their analgesic regimens with their physicians. In addition, the IN advised them on how to manage side effects, in particular constipation.

Patient: Before I had a bloated stomach and no bowel movement at all. And now I have it basically under control!

FC: And she (IN) really supported you and told you how to [take it].

At the end of each intervention session, patients and FCs set individual goals and agreed on a symptom management plan for the coming week, which were reviewed and adapted weekly. These goals motivated participants to be more active and to implement the pain management plan.

Patients and FCs experienced the IN as a competent coach. That is, she listened attentively, provided comprehensive explanations, had sufficient time, and was able to answer specific questions about analgesics and symptom management. While she responded to each patient's experiences with analgesics and side effects, she took into account the individual's level of knowledge, skills, and characteristics. In addition, participants perceived the IN as trustworthy; in fact, they trusted her enough to change their behavior based on her advice.

Learning processes were facilitated or hampered by a number of patient characteristics. While most patients' and FCs' learning progressed, some did not change. Patients who reported less pain and fewer side effects learned more easily. These patients were more willing to take their analgesics and mentioned decreases in fears and concerns. FCs functioned as an important support in implementing the pain self-management tasks. In contrast, declining health status, severe side effects, and/or forgetfulness seemed to limit patients' abilities to implement pain self-management. In addition, if patients ignored FCs' advice regarding analgesics, FCs felt stressed and unable to support the patients.

3.3.3. Experiencing success improved pain self-management strategies

After the intervention, participants' pain experiences varied. Some patients seemed unable to implement adequate self-management practices due to disease progression. However, most of the IG participants reported increased knowledge about ATC and PRN medications and experienced pain relief. These patients and FCs felt more confident to independently adjust their analgesic doses. Moreover, successful experiences reduced their fear of side effects and patients took their ATC opioids more regularly. They became more active, visited friends and relatives, and had a more positive outlook about the future. In addition, they learned to use the diary as a supportive tool. The ability to review previous entries supported IG participants to learn how to react to new or increased pain and related symptoms.

Patient: Yes, [I feel] very well, because I learned a lot from Mrs. S. [IN]. And that makes me feel more secure.

3.4. Illuminating learning processes from two perspectives

The mixed methods approach that was used to further explore

learning processes on a case-by-case basis showed that some participants' pain did not decrease, even though their pain management knowledge and self-efficacy slightly increased. The qualitative data provided explanations and insights into why some patients did not benefit from the intervention. Difficult family situations, an unstable health status, and/or forgetfulness prevented the implementation of an adequate pain self-management plan. In contrast, pain self-management strategies were implemented more successfully, when participants had a stable health status and experienced pain relief without burdensome side effects. Two contrasting cases illustrate these findings (Fig. 2A–B).

The integration of PPQ/FPQ scores and qualitative data on pain knowledge in the meta-matrix (Steinmetz-Wood et al., 2019) further explained participants' ratings of PPQ/FPQ items. While the total mean score for the PPQ in the IG increased over time, the increases varied widely among single items (Supplementary Fig. 1). The analysis showed three patterns (Table 3 provides illustrative examples from the metamatrix): Participants' ratings were guided by their experiences rather than through information provided during the intervention, e.g., some patients who were still in pain would rate item #1 low even though they had learned that cancer pain could be relieved. Second, contradictory ratings and statements indicated misunderstandings regarding the items on psychological addiction (#3) and physical dependence (#4). Third, some items (e.g., #9) were easily understood and ratings were based on pre-existing knowledge or knowledge acquired during the study.

4. Discussion

This study is the first to evaluate learning processes associated with a psychoeducational cancer pain self-management intervention and to use a mixed method approach to achieve this goal. Consistent with previous studies (Kim et al., 2004; Koller et al., 2013; Rustøen et al., 2012), IG participants' pain management knowledge improved significantly. Moreover, our results suggest improvements in IG participants' self-efficacy. This outcome has rarely been investigated in previous studies (Oldenmenger et al., 2018). Furthermore, patients' and FCs' learning was strongly supported by a competent and trustworthy IN who tailored the intervention to each individual's needs.

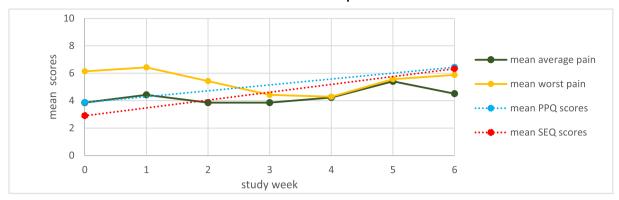
As our integrated findings illustrate, participants' answers to the PPQ/FPQ were based on their own experiences with pain management rather than on their knowledge of it. This observation may partially explain Rustøen et al. (2012) conclusion that it is not entirely clear how knowledge is related to changes in pain management behaviors. Knowledge alone may not suffice. The experience of pain relief, as well as a reduction in side effects, may be necessary to motivate changes in self-management strategies. This hypothesis is congruent with Bandura's SCLT principle that successful experiences have the strongest positive impact on self-efficacy and future behavior, whereas failures likely undermine both (Bandura, 2001).

At enrollment, and consistent with previous studies (Kim et al., 2004; Rustøen et al., 2012), participants scored lowest on the PPQ/FPQ item that is related to the amount of analgesics given (i.e., item #5). This finding suggests that participants had little knowledge, but feared the development of tolerance.

Regarding fears of psychological addiction (#3) and physical dependence (#4), ratings of participants and their statements remained contradictory in spite of ongoing explanations by the IN. One reason for this finding could be difficulties in understanding the German PPQ/FPQ items #3 and #4. These items should be further explored based on patients' feedback and adapted accordingly.

A trustworthy relationship with a knowledgeable IN supported participants' learning processes (Kasasbeh et al., 2017; Kwon, 2014). A trustful relationship and open communication with competent clinicians was found to improve oncology patients' knowledge, as well as their ability to manage other symptoms and side effects associated with their cancer (Ekwall et al., 2011; Hjorleifsdottir et al., 2008). In addition, as noted in our data, FCs play pivotal roles in pain self-management

A. First case example



B. Second case example

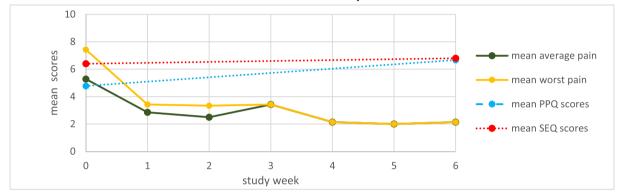


Fig. 2. Case examples illuminating (A) a negative and (B) a positive example for IG participants' learning processes over the course of the study. *Note*. Abbreviations: ATC = Around the clock; BTP = breakthrough pain; PRN = pro re nata (as needed); PPQ = Patient Pain Questionnaire; SEQ = Self-Efficacy Questionnaire.

because they provide psychological and physical support (Ferrell, 2019).

Individualized coaching sessions that were adapted to patients' experiences, needs, concerns, and knowledge gaps, enhanced IG participants' pain management knowledge, self-efficacy, and learning. In particular, reviewing their diary entries and enhancing knowledge through key information and positive reinforcement by the IN (i.e., academic detailing, O'Brien et al., 2007; Soumerai & Avorn, 1990) enabled participants to better manage new or increased pain and analgesic side effects. Our findings are consistent with previous studies that documented the usefulness of a pain management diary in combination with personalized intervention sessions (Miaskowski et al., 2004; Rustøen et al., 2014; Schumacher et al., 2002).

As our mixed methods findings suggest, patient characteristics influenced participants' learning processes; that is, declining health hampered learning and subsequently pain self-management. Previous research has linked personal characteristics (e.g., distress, cognitive deficits) with patients' behaviors and adaptive coping strategies (Colley et al., 2017; Lai et al., 2019; Langford et al., 2020). These findings suggest that very sick patients and their FCs may need more than a psychoeducational intervention. Their situations may call for more direct support in pain self-management.

Some study limitations need to be acknowledged. First, the sample was small. A number of recruitment challenges were encountered including: an overestimation of the number of eligible patients by clinicians; an underestimation of the number of eligible patients who would decline participation (i.e., 82% of patients, who were approached declined partly because of concerns regarding additional burden); and a certain level of "gate-keeping" by the RAs who did not approach every eligible patient that explain the long recruitment period. The small and rather heterogenous sample of patients with various types of cancer, as

well as the short follow-up period limits the generalizability of the findings. In addition, the qualitative sample does not necessarily represent the RCT sample as a whole, as we interviewed only participants who completed the trial. Strengths of this study included its rich qualitative data and mixed methods approach, which provided a more comprehensive understanding of participants' learning processes than either a separate quantitative or qualitative approach could have done.

5. Conclusions

Additional research is warranted to evaluate the influence of FCs' pain management knowledge and self-efficacy on patients' pain scores and their self-management strategies. Based on our findings, competent and trustworthy nurses could provide individualized interventions to support patients and FCs in their pain self-management. Using a diary, jointly reflecting on the documented experiences, and addressing knowledge deficits and misconceptions through the use of academic detailing can facilitate patients' and FCs' learning processes.

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CRediT authorship contribution statement

Sabine Valenta: Conceptualization, Methodology, Formal analysis, Investigation, Writing - original draft, Visualization; Christine Miaskowski: Conceptualization, Methodology, Writing - Review & Editing, Visualization, Supervision, Funding acquisition; Rebecca Spirig: Methodology, Writing - Review & Editing, Supervision, Funding acquisition; Kathrin Zaugg: Methodology, Writing - Review & Editing, Supervision, Funding acquisition; Horst Rettke: Writing - Review & Editing, Project

Table 3

Examples of the mixed methods meta-matrix showing items and scores of the Patient Pain Questionnaire (PPQ) and Family Pain Questionnaire (FPQ) in the intervention group at enrollment and after 6 weeks aligned with qualitative data.

Exemplary items of the PPQ/FPQ	Timepoint of measurement	Scores on the PPQ ^a / FPQ ^b	Representative quotes on the PPQ/FPQ items ^c	Patterns
Item #5 It is better to give the lowest amount of pain medicines possible early on so that larger	At enrollment	0	Pat.: "Yes, this is also related to the previous question, where I have the feeling that in the beginning I should start as slowly as possible!"	Responses based on experiences
doses can be used later if pain increases.	After 6 weeks	10	IN: "And that's true again: Well, it's important not to be cautious in the beginning, and think you have to save the larger dose for later, because with Targin you don't have an upper limit." Pat. "I've had that experience, yes."	
Item #4 Most cancer patients on pain medicines will become physically dependent on the medicines over time.	At enrollment	8 <u>FPQ</u> 0	Pat.: "Yeah, well, Dr. Z. told me that if you want to stop it, then you have to taper it off, right?" FC: "I had understood it that way, when the daughter received morphine. Then I asked the question and they said, no, you don't become addicted and you don't have to be afraid that she will have an affinity to it later."	Contradictory responses due to misunderstandings
	After 6 weeks	2 <u>FPQ</u> 10	FC: "Yes, because of the tapering off. That's why we said that. The body gets used to it, so you shouldn't stop it abruptly. You did it right the last time." Pat.: "Yeah, true." FC: "And I did it wrong" (laughing)	
Item #9 Patients are often given too much pain	At enrollment	4	Pat: "Yes, that's just my feeling, when I look at my medicine cupboard and see what's lying around."	Responses based on previous or acquired
medicine.	After 6 weeks	10	IN: "So people are not being given too much, but people are themselves on the brakes." Pat: "Yes, but thanks to you and the time we have discussed this issue with each other, yes."	knowledge

Note. a 0–10 scale: Higher scores reflect more knowledge. b FPQ scores only indicated if FC has participated with this patient. c For each item, the quotations are from one and the same patient (respectively FC) at the beginning of the study and after 6 weeks. Abbreviations: FC = family caregiver; FPQ = Family Pain Questionnaire; IN = intervention nurse; Pat = patient; PPQ = Patient Pain Questionnaire.

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