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Contents

Review

Patients' Participation in Health Research: A Classification of Cooperation Schemes

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Abstract

Background: The number of academic papers referring to patient engagement or to related terms has been rising sharply for at least 20 years; several review articles have recently been published enumerating a wide variety of situations of patient involvement in research and partnership with health professionals.

Objective: As no standardized keywords and no shared classifications exist to facilitate comparative studies of situations where patients and their organizations are recognized as coresearchers, this paper purports to create a typology to analyze those situations.

Methods: Based on 8 already existing meta-reviews or related studies, this work is achieved using a template based on Claude Bernard's conceptualization about experimental medicine.

Results: This typology allows differentiating between modes of involvement and levels of patients reflexivity mobilized in evidence-based medicine (EBM) trials. Screening through a first set of various meta-reviews using this typology shows that a high level of reflexivity is seldom observed and seen only when a patient organization (PO) is involved in the process. This suggests that such an organization can play several roles essential to high reflexivity trials; the PO is capable not only of grouping singular approaches but also of synchronizing and correlating them. However, as nowadays health researchers and POs give more attention to syndromes or troubles for which EBM clinical trials are not relevant due to lack of biomedical indicators (eg, fibromyalgia, chronic fatigue syndrome, or psychiatric disorders), a supplementary mediation category is added to take into account action-research, community-based participatory research, and grounded theories.

Conclusions: With this new category, this typology should be able to classify most of the cooperation schemes and thus be a useful tool for the next systematic reviews.

Introduction

The number of publications mentioning patient engagement and related terms such as patient involvement or patient participation reported through PubMed has strongly increased for at least 2 decades, as shown on Figure 1.

Screening those publications shows that the uses of the terms patient engagement, patient involvement, and patient participation have developed concomitantly over the last few years without any clearly defined differences in acceptance. Most works use one of these terms without specifying why they have chosen it, either because authors consider them synonymous or because they do not feel the need to justify their

choice. More generally [1], bibliometric approaches to those issues reveal weak efficiency and relevance due to a lack of shared keywords linked to a good typology that could enable involvement in protocols to be compared. This is confirmed by the work of Domecq et al [2], which shows that among the 5551 recent papers mentioning patient engagement, only 142 give useful data about the way those patients have been involved in protocols.

It results from this situation that, although the recognition of patient experiential knowledge (PEK) has reached the level of a social fact attested by diplomas, jobs, laws, and academic concepts [3], no standardized keywords and no shared typology can actually be used to facilitate comparative studies of situations where patients and their organizations are recognized as coresearchers. As Domecq et al [2] have recommended that "bibliographic databases use indexing terms that identify active patient engagement in research to facilitate future research in

this field," it is obvious that progress requires methods and typologies to describe which role PEK plays in health research and how to reduce the risks of tokenism.

In this context, this paper aims at creating a classification embracing patient opinions and approaches as well as those in which patient contributions based on their PEK are accepted in their own right (ie, where patients are fully accepted as coresearchers).

From a methodological point of view, without shared keywords, ascendant clustering converging to a semantic-based taxonomy is not possible. Therefore, our aim cannot be to create a taxonomy based on a bibliometric or lexical study but rather to formalize a complete classification (a set of rational categories)—that is to say, a categorization which allows us to specify major types corresponding to the main ways in which patients and academic researchers associate today.

Figure 1. Ratios of publications mentioning patient commitment, patient involvement and patient participation compared to those mentioning pneumothorax and psoriasis in their titles and abstracts according to PubMed data. The slower growth of the patient empowerment ratio was also indicated as a reference. All curves are approximated by 4th degree polynomials (Microsoft Excel).
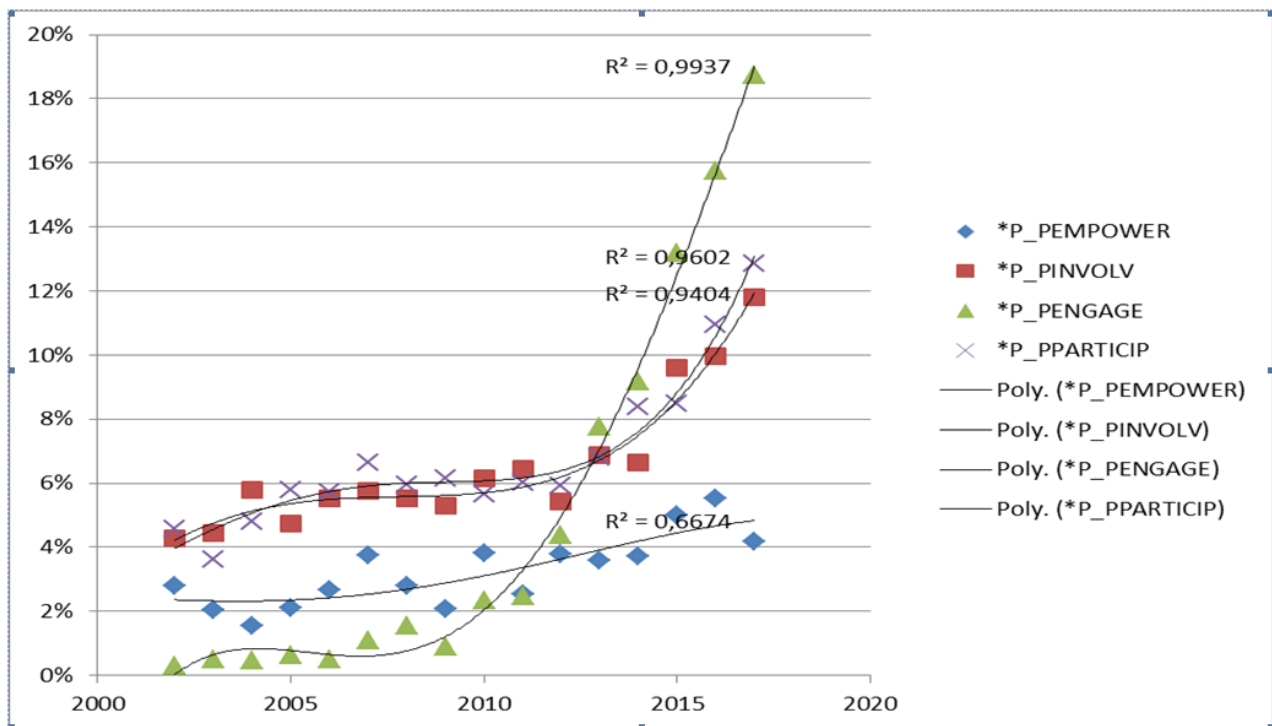
Methods

A Typology Able to Indicate Different Levels of Patient Reflexivity

Thanks to previous studies [3], we began this work intending to distinguish at least 2 categories characterized by different levels of patient reflexivity: on the one hand, cooperation in which patients were only associated with data collection, and on the other hand, cooperation in which they were associated also with design or conclusion. Thus, we imagined a working method in 2 steps, aimed at obtaining a typology validated by a completeness test.

- Step 1: Look for a template or grid able to describe the phases in which the cooperation would be mobilized or not (we used a very simplistic description of Claude Bernard's experimental medicine [4]).
- Step 2: Using this model, screen a corpus of papers embracing the broadest types of patient cooperation with 2 aims: validate the best set of categories capable of accounting for the diversity of cooperation encountered and be sure that any kind of cooperation could fit in one of those categories.

Due to the keywords issue, instead of creating a new minute, even pernickety, review of primary literature, we decided for step 2 to use already published meta-reviews such as those quoted above. Our first idea was to select them through a

systematic search on PubMed. However, similar problems of terminology relevance arose. Queries on PubMed titles or abstracts for review and patient engagement (152 reviews found), patient involvement (246) or patient participation (275) provide too numerous results; 642 different reviews are found with 1 of those 3 terms. Therefore, we opted for a pragmatic, targeted selection and chose a small set of 8 complementary meta-reviews that were already often quoted:

- Four general syntheses and descriptions concerning situations of coresearch found in medical literature [1,2], cases of PEK recognition [3], and training partnership actions [5]
- Three more specific meta-reviews: autoethnography [6] and mental health user involvement [7,8]
- An eighth review paper dedicated to inventory and description of the European Patients' Organizations in Knowledge Society (EPOKS) [9]

We added this last review paper because we wished to take both collective and individual cooperation into account.

A Template Inspired From Claude Bernard's Model

As explained previously, our first goal was to be able to distinguish different levels of reflexivity recognized by patients; therefore, an easy-to-use description of current research protocols was needed. To build a first version of the typology itself, we elected to use a system of description inspired from a simplification of Claude Bernard's formalization of experimental medicine [4]; this idea was first presented in Jouet et al [3]. This model, called OHERIC, divides investigations into a pragmatic grid: initial Observation, Hypothesis, Experiment proper, Result, Interpretation, and Conclusion (see Table 1).

This OHERIC grid is introduced only to be used in a quite pragmatic way as an ideal type description or a computational intermediate (ie, a background against which to set the practices we aim at describing). In view of the critic of linearity, we give no specific chronological significance to OHERIC phases, which can then be considered as aspects of the same process that can overlap or even interpenetrate.

The OHERIC pattern can be used to build grids in which arrows specify who exerts the main reflexivity at each stage of the research. Up arrows specify a nonacademic origin (bottom-up process), while down arrows designate an academic origin. This appears close to the stages of research process as described in the *Handbook of Service User Involvement in Mental Health Research* [8], as is shown in the third line of Table 1. Referring to autoethnography led by a patient [6], the fourth line shows that OHERIC can also be compared to Dewey's self-inquiries [10].

Figure 2 shows how this encoding allows comparing 2 such protocols: an evidence-based medicine (EBM) randomized placebo-controlled trial and an autoethnography.

Table 1. Phases of an investigation described with the stages of Bernard, Wallcraft, and Dewey.

OHERIC phases	O[a]	H[b]	E[c]		R[d]	I[e]	C[f]
Bernard's research phase [4]	Initial data or observation leading to research	Putting forward a research hypothesis	Building an experimental device, inventing a test	Collecting observations, realizing a test	Processing results and data	Interpreting results	Scientific conclusion
Walcraft et al "Involvement in Mental Health Research"	Identifying a research topic	Designing research	Outcomes measures	Data collection	Data analysis	Interpretation	Write up and dissemination
Dewey's phenomenology "How we think"	A felt difficulty; its location and definition	Suggestion of a possible solution	Development by reasoning of the bearings of the suggestion	Further observation and experiment	Leading to its acceptance or rejection (1)	Leading to its acceptance or rejection (2)	That is, the conclusion of belief or disbelief

[a]O: initial observation.

[b]H: hypothesis.

[c]E: experiment proper.

[d]R: result.

[e]I: interpretation.

[f]C: conclusion.

Figure 2. Comparison between 2 protocols for chronic diseases.

OHERIC	O	H	E1	E2	R	I	C
(1) Standard EBM randomized placebo-controlled trial	↓ Application 'as is' of an academic protocol			↑ Realized by each patient	↓ Application 'as is' of an academic protocol		
(2) Patient auto-ethnography [6]	Patient observing his symptoms, person collecting data	Searching for a care strategy	Implementing care strategy	Patient rationally tending to himself (dosage)	Patient rationally tending to himself (observation)	Patient drawing conclusions from the effects observed of his care	↑

Results

First Typology Distinguishing Low and High Reflexivity Engagement

Such a template can easily be applied to the clinical trials in EBM because they are based on protocols that are close to the OHERIC phase sequence. Therefore, it is quite easy to create a first classification defining different levels of mobilization for the patients' reflexivity. Concerning patients associated with this kind of trial, OHERIC grids allow us to distinguish 2 main types of roles: (1) patients and their relatives were mainly considered as mere data collectors and (2) more diverse situations that all had a fact in common—patient reflexivity (ie, PEK) was at the heart of the research process.

More precisely, category 1 corresponds to an involvement of patients and relatives as data collectors in the E phase of OHERIC. Collected data may consist of personal opinions and biomedical parameters (eg, blood pressure, glycemic measurements) or self-evaluation according to one's own perception (eg, pain, anxiety, discomfort) or opinion [11,12].

In some cases belonging to this first category, patients are also associated with part of the processing of the data collected (OHERIC R). As this has the effect of reinforcing their reflexive activity, we decided to characterize these situations through a new category we named 1+. At this step, we can mention that it could be relevant to distinguish the collection of opinions from the collection of biomedical parameters (either quantitative or qualitative) through 2 more subcategories 1_{OP} (opinions) and 1_{PA} (parameters). We will see later that this first subcategory, 1_{OP} (opinions), has to be merged into a larger one (ie, M category).

Category 2 collects situations where patients and relatives contribute with their reflexive capacities to other phases besides data collection or initial processing. We first distinguished 2 subcategories in it: 2 for participatory EBM and 2+ for a full popular epidemiology process.

The subcategory 2 or 2_{ParEBM} was created to characterize situations corresponding to what we can call participatory EBM where academics decide to involve—in parallel to the main EBM process—lay people's reflexivity for all research phases following the initial set-up (ie, all OHERIC but O or perhaps E).

The second subcategory, 2+ or $2+_{PopEpi}$, is inspired by Brown's research in medical sociology [13]; Brown has introduced the term popular epidemiology in reference to parents and teachers confronting a cluster of childhood leukemia (the Love Canal School case, named after a polluted area near Niagara Falls) who could keep control as well over the subsequent phases. Such autonomous grasp (OHERIC) of a medical problem by a concerned community obviously raises issues concerning differences in social representation of expertise [14]. Figure 3 summarizes those categories and subcategories.

Figure 3. Categories and subcategories of types of involvement for patients and relatives as coresearchers in medical research projects.
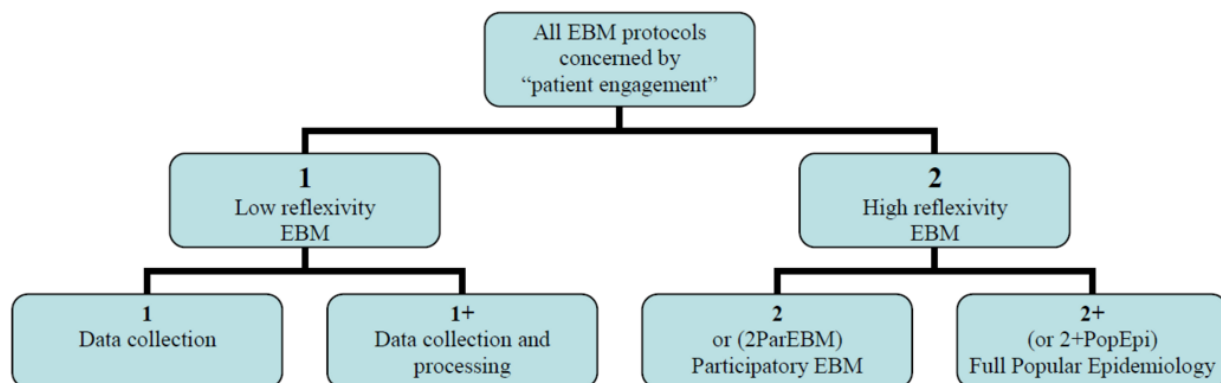
Findings Concerning Patient Organizations

The Significant Role of Patient Organizations in High Reflexivity Cooperation

Screening the publications quoted in meta-reviews shows that individual patients are seldom recognized as contributing fully to the reflexive production of new knowledge. As a matter of fact, in category 2, real research responsibilities are entrusted to collective community actors rather than to individual patients, who find themselves restricted to type 1 functions (ie, data collection). Such intermediary collective actors may be whole communities, mutual assistance groups, or patient organizations (POs).

By providing a framework for collective action and investigation, these POs not only help patients develop their individual reflexivity and ability to compare their situations but also lead patients to synchronize them. Collective, synchronized patients' reflexivity and investigations become then more readily describable in the language of a collective protocol taking on the form of a succession of stages akin to the OHERIC formalism.

If we adopt the spiral-shaped representation of the individual pragmatic forms of thinking (in the sense of the curls proposed—in addition to Dewey's work—by Ashby [15]), we can consider that these POs carry out a work of standardization and of unfolding those individual curls, in a process similar to an uncurling or a straightening.

Furthermore, once started, such a PO producing an OHERIC-type protocol aggregates the incoming patients by putting them literally in sync with those already included. And it is precisely because the work accomplished by the PO is then collectively turned into hypothetical-deductive parlance thanks to this unfurling that it is made acceptable in type 2 projects without endangering the criteria of the academic patterns according to which new medical knowledge is produced. POs then fulfill a role of socializing and reformulating each individual patient's metacognition and reflexivity, allowing them to be taken into account by academic research teams as intellectual inputs. Furthermore, these POs may also be places where collective inquiries can be decided, either invented by the patients themselves or suggested by relatives, caregivers, clinicians, or researchers.

The collectivization of reflexivity operated by a PO can act during different OHERIC phases: Observation and Hypotheses, through the collective problematization or formalization of the issue (this includes issuing a hypothesis that can be tested through collectively taking/acquiring a critical distance from situations experienced individually); Experience and Results, as a self-training framework in which patients learn how to observe and tend to themselves (and sometimes as a furnisher of note-taking tools, multiple choice questionnaires, or quantified self-tools); and Interpretation and Conclusion, by organizing the formalization of conclusions. Figure 4 abstracts the different roles played by POs and locates them along OHERIC phases.

Figure 4. Potential effect of a patient organization according to research categories.

Categories of research		O	H	E1	E2	R	I	C	Pub
1	Patient data collection	↓	↓	↓	Helping to implement the protocol ↓↑	Helping in collecting data ↓↑	↓	↓	↓
1+	Patient data collection and processing	↓	↓	↓	Helping to implement the protocol ↓↑	Helping in collecting data ↑	Contributing to processing ↓↑	Helping with processing ↓↑	Formalization of a collective conclusion ↓
2 Ebm Par	Participatory EBM	Collective observation and synchronization ↓↑	↓↑	Formulation of a shared hypothesis ↓↑	Helping to implement the protocol ↓↑	Collective adaptation of the protocol ↓↑	Pooling of observations and results ↓↑	Helping for processing ↓↑	Formalization of a collective conclusion ↓↑
2+ Pop Epi	Full Popular epidemiology	Emergence, collective observation and synchronization ↑	Collective formalization of the issue ↑	Formulation of a shared hypothesis ↑	Elaborating the protocol ↑↓	Collective adaptation of the lay protocol ↑↓	Pooling of observations and results ↑↓	Processing ↑↓	Formalization of a collective conclusion ↑↓

A Three-Layer Point of View: Patients' Dewey Pragmatics, Bernard's OHERIC, and Evidence-Based Medicine Trials

From an epistemological point of view, it can be said that the multiple interactions between various patients through a PO bring about a reshaping of their singular pragmatic phenomenology into a kind of investigation relevant for EBM researchers (eg, in a collective process that fits with Bernard's experimental medicine). Therefore, we may represent interactions between the patients and the academic researchers using a 3-layer model: pragmatic phenomenology (Dewey's level) is linked to experimental method (Bernard's level) through PO interaction, and these 2 levels are themselves linked to the third one (EBM clinical trials). Textbox 1 shows the superposition of these 3 layers. It shows the role of the POs between patient pragmatic phenomenology and EBM in type 2 or 2+.

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Textbox 1. Three layers model for 1 and 1+ or 2 and 2+ types.

Level of global scientific research:

Clinical trials developed in evidence-based medicine epistemology [16]

Level of rational work, local or in group:

OHERIC-describable protocols [4]; work in a patient organization may allow relating experiential knowledge acquired through pragmatic phenomenology to evidence-based medicine protocols

Level of individual experiential knowledge:

Dewey's pragmatic phenomenology of each patient [10]

High Reflexivity Without Patient Organizations?

In the EBM clinical trials point of view [16], this led us to the conclusion that patient reflexivity and lay production of knowledge are taken in account by EBM clinical trials only if their results are adapted or translated into a format allowing their description through an EBM protocol. The uniquely possible agents of this translation seem to be those POs that indeed appear to play an intermediary role, socially as well as epistemologically; without any PO to translate between individual pragmatism and OHERIC protocol, academic researchers stick to category 1, asking patients to bring data in phases ER, doing the work in phases OH and IC themselves. They tend not to engage in leading patients through category 2, a work they may consider unnecessary or outside their capacities. They may, however, set up devices to listen to patients' voices [1,2,11,12] or train patients as cotrainers and peer experts [3].

However, when researchers following EBM protocols realize they need to take into account not only biomedical data but patients' reflection as well, they themselves may try to foster the creation of POs, either in cooperation with the patients or with economic actors as manufacturers of health products or health insurers. Meta-reviews show that with the great expansion of interest in mobile phones and other connected objects, numerous cooperation programs have now been established between researchers, mHealth companies, and POs, either preexisting or specially created for this purpose.

Addition of a Mediation Category

High Reflexivity Outside or Beyond Evidence-Based Medicine Clinical Trials

Of course, cooperation between patients and academic researchers is not limited to the pattern of clinical trials in EBM. The existence of other cooperation schemes is easy to verify through an analysis of more specific corpora (ie, mental health [7,8] or autoethnography–oriented [6] reviews). Screening recent reviews about patient engagement shows that eHealth or mHealth new cooperative programs go far beyond the scope of EBM clinical trials. As we open our field of observation to human sciences disciplines such as sociology, anthropology, or ergonomics, it is easy to observe that participatory situations of knowledge construction are frequent and very diverse.

In fact, the POs have different postures regarding cooperation with health researchers, and EPOKS's evidence-based activism [9] or Epstein's impure science [14] are describing other

schemes besides a simple allegiance to EBM clinical trials. Nowadays, some of the POs choose to adopt the posture that we described in Figure 3. This may cover both the 2 and 2+ categories, depending on whether the POs were the promoter of the protocol: it is the case in 2+ (OHERIC where PO promotes the research and then associates with medical research teams or even mHealth apps or services) and not in 2. But in fact, many other POs do not focus on promoting the collective comparison and reflection on individual situations to bring data to EBM. On the contrary, several POs (for instance, those concerned with psychiatric disorders or syndromes not directly linked with biomedical indicators) criticize what they see as too narrow a conception of knowledge coproduction in EBM (ie, an exclusively positivist anchorage of EBM built on the idea that evidence must only result from an experimental procedure related to hypothetical-deductive assumptions).

In an intermediate posture between what we can call allegiance to the EBM and radical opposition to it, many POs are focused on individual strategies and folk theories and on developing intersubjectivity through the transformation of individual experiences into narratives or accounts that can be shared.

M Category as a Way to Go Beyond the Evidence-Based Medicine Research Limitation

As a matter of fact, when data consist only of isolated patients' dispersed and unsynchronized lived accounts, EBM (particularly clinical trials) has the effect of drastically limiting the potential contributions of patient reflexivity to the construction of new health knowledge (see, for instance, Faulkner and Thomas [16] for mental health). If phenomena can be observed only through the perceptions of the patients and their relatives (as is the case for anxiety or pain in cases such as fibromyalgia, for instance) and treatment efficiency cannot be studied without listening to them, researchers need to open more opportunities for the bottom-up transmission of patients' lived-through experiences, however different and even heterogeneous they may appear. How can researchers bring such reflexive materials to convergence not only in case-by-case individual experiential knowledge but also in a corpus that can be used to produce innovative health knowledge?

We thought it necessary to distinguish between these different cases while still retaining the already mentioned 2, in which we had specifically included EBM research projects organized beforehand to entrust patients with specific functions that can be described through a OHERIC framework (eg, a patients' group organizing and analyzing specific biographic workshops to collect qualitative data in order to compare various evaluation

processes of the effectiveness of a long-term treatment on pain perception).

Hence we decided to define, besides the main categories 1 and 2, a third category called M (as for mediator in the sense of facilitators) to collect cases where patients were used as intermediaries, facilitators, or even multipurpose interpreters [17]. With such a wide definition of our M category, any kind of research dedicated to collect only patients' opinions (but not feelings) belongs to M type, and category 1_{OP} turns out to be useless, as it appears to be one of the M subcategories.

For that purpose, M ethnological protocols offer an alternative to the Dewey-OHERIC-EBM translation. It relates to the patients in both a more heuristic and comprehensive manner, as is shown in Table 2.

Practically, patients are no longer seen only as witnesses bringing data to hypothetical-deductive epistemologies. Constructions of folk and academic types of knowledge can then be put into relationship under the condition that other tools are brought to the core of the protocols: tools of description of patients' relationships to their illness as well as tools of production of innovating knowledge, using not only hypothetical-deductive models but also more comprehensive methods, such as grounded theory [18], for instance.

Recognizing Coresearchers Outside of Evidence-Based Medicine

The recourse to ethnological protocols is not the only approach found by researchers to short-circuit the Dewey-OHERIC-EBM translation and allow the setting up of other bottom-up chains of production of knowledge. Other disciplines are used in M category to blend with the benefits available from patients' and relatives' pragmatic phenomenology in order to achieve more efficiency and hence more confidence and observance from its beneficiaries. This is, for instance, the case with educational science for research on PEK [3], ergonomics for research on patients' voices [2] or patient preferences [19], and, of course, information-communication for numerous studies of eHealth.

Table 3 is a complement to Figure 3, focusing on M category. It gives a list of those nonmedical disciplines (this list is only indicative as several other epistemologies can also contribute to new knowledge production in health), and Figure 5 shows a refined tree of categories.

Table 2. Three layers model used to compare 2 regimes of connection between pragmatic phenomenology and global knowledge production.

| Coupling model	EBM[a] clinical trials regime through patient organizations and Claude Bernard	Full participatory action research non-EBM regimes
Types	1, 1+, 2, 2+	M
Level of global scientific research	Epistemology of the EBM [16]	Epistemologies of comprehensive research (such as action research [17] or grounded theories [18])
Level of rational work, local or in group	OHERIC[b]-describable protocols [4]; work in a patient organization may allow relating experiential knowledge acquired through pragmatic phenomenology to EBM protocols	Comprehensive organization through participatory M category action research
Level of individual experiential knowledge	Dewey's pragmatic phenomenology of each patient	Pragmatic phenomenology of each patient

[a]EBM: evidence-based medicine.

[b]OHERIC: initial Observation, Hypothesis, Experiment proper, Result, Interpretation, and Conclusion.

Table 3. Examples of subcategories for M type based on disciplines contributing to knowledge production in complement to evidence-based medicine.

M sub- categories	M anthropology	M psycho-sociology	M politics and economics	M education	M info-communication	M ergonomics
Concepts, facts studied	Culture, ethics, knowledge, and beliefs	Social representations	Health governance, users' representation, health democracy, activism	Knowledge, abilities, self-education, learning	Connected tools, networks, quantified self, patient 2.0, eHealth	Adaptation of artifacts, prosthesis, customer made

Figure 5. Completed typology tree.
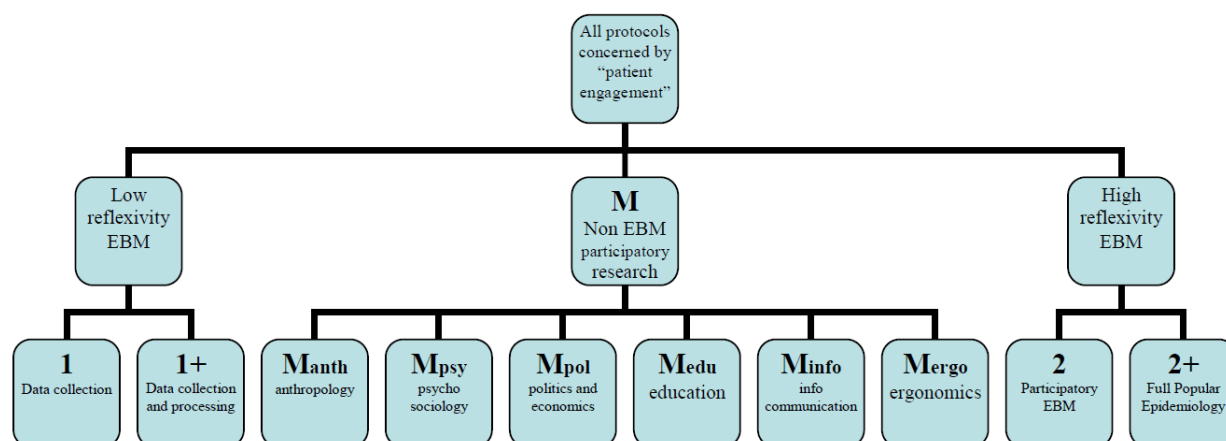
Discussion

Building such a typology also addresses the question of the social representations of research. Our hypothesis is that these representations are dependent on the need to associate lay people as producers of data, producers of PEK, and even as coresearchers: the greater the need to involve communities to obtain scientific results by using their (individual and collective) reflexivity, the greater the resulting shift by research bodies toward epistemologies more open to taking into account lay people's pragmatic phenomenology.

Health research as a social construct negotiated among stakeholders: with the rise of impure science [14], evidence-based activism [9], and recognition of PEK [3], researchers can no longer remain confined in their ivory towers. Academic imperatives are not only exposed to the negative influence of economic issues but also to positive activist irruption by the concerned communities and even to their necessary involvement in the process: the more the objects of study also become subjects of studies and express their demands that the reflexivity of lay people be listened to (eg, studies on perceptions, feelings, representations), the more the epistemologies must adapt and accept their own articulation with the concerned people's pragmatic phenomenology.

The main question is neither to determine whether academic knowledge obtained via clinical trials in EBM is worth more than patient knowledge experienced from synchronization of singular phenomenologies nor to choose the best model of knowledge production between Bernard, Dewey, or Lewin; on the contrary, it is now to find ways to make all those contributions converge. The more researchers must steer between the taken-for-granted representations of the world of lived experience and the ideal types of proof-finding, the more they will have to balance multiple ways to define how health research can be done.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Lexical analysis illustration of PubMed papers about "patient engagement" obtained by the author (Olivier Las Vergnas) using Iramuteq and R open source softwares.
[JPG File , 103 KB - jopm_v9i1e16_app1.jpg]

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Abbreviations

EBM: evidence-based medicine
EPOKS: European Patients' Organization in Knowledge Society
OHERIC: initial Observation, Hypothesis, Experiment proper, Result, Interpretation, Conclusion
PEK: patient experiential knowledge
PO: patient organization

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Narratives, Perspective

Should Hospital Patients Have Bedside Access to Their Complete Medical Records?

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KEYWORDS

Acute patient portals; patient portals; PHR, medical records; transparency; note-sharing

Steven Jones finally received his heart transplant just two months shy of his 51st birthday. After 7 months spent lying in a hospital bed, unable to walk, transplant felt like the light at the end of the tunnel. "I thought life would return to normal after transplant," said Mr. Jones. "But that just wasn't true."

The Heart Institute at Columbia University Medical Center provides care for cardiology patients, including heart transplant recipients. In August 2016, the institute began a first-of-its-kind initiative. Patients received bedside access to their entire medical record, including clinical notes, through an online patient portal.

After Mr. Jones's transplant, a series of rejection events complicated his clinical course. While hospitalized at Columbia University Medical Center, Mr. Jones volunteered for the initiative. "I thought I knew everything about my disease," he recalled. "But when my doctor offered to let me read my notes, I learned just how much I didn't know."

Two years ago, the federal electronic health record financial incentive program "meaningful use" prompted rapid adoption of online patient portals. Per meaningful use, hospitals must permit patients "to view online, download, and transmit their health information." In August 2014, just 10.4% of US hospitals met this requirement. By November 2015, 64.3% did. Because meaningful use requires that health information be released "within 36 hours of discharge," hospitals generally do not permit or encourage inpatient access.

Yet, clinicians and patients increasingly view full transparency as a moral imperative. Patient advocacy to access medical records and even participate in note writing began in the 1970s, concurrent with the medical movement rejecting paternalism. The 1996 Health Insurance Portability and Accountability Act guarantees patients' right to review their medical data. Proponents of transparency believe online patient portals actualize the HIPAA mandate, by overcoming barriers such as time delays and photocopying costs.

The OpenNotes consortium reports that over 10 million individuals now have electronic access to their primary care providers' office notes. In OpenNotes trials, four out of five subjects accessed their physicians' notes online when given the opportunity to do so [1]. In spite of OpenNotes' success, electronic note-sharing remains relatively unstudied outside primary care settings.

The Note-Sharing Initiative at Columbia University Medical Center

In a randomized controlled trial [2], our team introduced a bedside portal to cardiology inpatients at Columbia University Medical Center. The bedside portal incorporates multiple features, including medication summaries, diagnostic test results, and the inpatient care team.

The note-sharing initiative at the Heart Institute provided 10 patients with real-time access to their complete medical record on tablet computers. We utilized a modified version of our bedside portal that included physician notes. We reviewed system usage logs and performed qualitative interviews to evaluate patients' experiences.

Some participants reported initial anxiety about viewing their medical record. One patient reluctantly agreed to participate, and initially said: "I don't think I will look [at the portal], because I'd rather not know." But the next day, he said: "I felt anxious at first, but now I'm starting to look. I like to watch my weight go down—it makes me feel good to see how much fluid I'm losing…I don't understand everything in the notes, but it's amazing to see everything that goes into my care."

Most participants reported enthusiasm about viewing their record. Half voluntarily requested access outside the hospital, and one participant even volunteered to pay for access. He said: "I already learned how to use this [portal] here [in the hospital]…I don't want to use new software at home."

Participants navigated to the "clinical notes" feature most frequently, and spent more time using this feature than any other. One participant observed: "The notes were where I was really able to find out what was going on, where all the information was put together…I love being up to speed with [my physician]. When she comes in, she doesn't have to explain what's going on, because I already know."

Participants reported that portal access impacted their care. Mr. Jones related an incident where he noticed that prednisone had fallen off of his medication list. "I showed the nurse," he said, "who agreed with me that something wasn't right. She called the doctor, and within a minute and a half the prednisone was back on [my medication list]. And within another minute and a half, my nurse was back with the [prednisone] pill."

The Future of Transparency for the Medical Community

Patients benefit from having access to their complete medical record, including physician notes. Information can empower patients to participate in their care, and raise their awareness of providers' actions performed on their behalf. Information also lessens the anxiety, disempowerment, and suffering patients experience due to uncertainty about their condition. Our participants demonstrated a willingness to engage with complex information. This finding is consistent with previous research demonstrating that usage rates for note-sharing patient portals exceed rates for simpler portals [3,4].

Both proponents and opponents of medical record transparency support their arguments with strong ethical principles. Opponents argue that medical record information is too complex or too alarming for patients, and that full transparency violates the "first, do no harm" principle. Proponents reject such rhetoric as paternalistic, and support full transparency under the autonomy principle. Dr. Donald Berwick recently wrote that "anything professionals know about their work, the people and communities they serve can know, too, without delay, cost, or smokescreens" [5].

The pernicious effect of computers on the doctor-patient relationship is a widely cited problem in modern medicine. Transparency reinvents the computer as a tool to enhance, not detract from, the doctor-patient relationship [6]. Previous research suggests that transparency especially promotes greater trust among vulnerable patient populations [7]. Referring to the broader health care system, Mr. Jones said: "I don't trust [it], so I'm happy about this information [on the portal]…I feel better able to cope."

As value-based payment programs gain momentum, an era of consumer-driven health care may be imminent. The question, then, becomes not "if" hospitals will provide real-time access to patients' complete medical records, but rather "how" and "when." We owe it to our patients and to ourselves to thoughtfully research transparency and its associated ethical concerns. All of us strive to give patients the best possible information, and if we discover that transparency furthers this goal, we must provide it.

Authors' Note

Patients' names in this paper were changed to preserve anonymity. Quotations were edited for clarity.

Conflicts of Interest

The authors have declared that no competing interests exist.

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Communication at Transitions: One Audacious Bite at a Time

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Abstract

To be audacious and take significant steps toward achieving the Quadruple Aim (improving the patient experience of care; improving the health of populations; reducing the per capita cost of health care; and improving the work life of clinicians and staff), we patients and caregivers need to better understand key features of our health journeys. When on that health journey, we are patients interacting with a series of care teams: our home team (social network), our community agency teams, our emergency care team, our hospital teams, and on and on. These care teams include ourselves, our caregivers, clinicians, other professionals, and direct care and support staff—people at the center of care. The actions taken by people at the center of care to improve, maintain, or adapt to our health or illness represents our health care. Actions can be diagnostic, taking medications, undergoing procedures, learning, living life and getting help living life. So, our health journey is teams of people at the center of care taking such actions to provide healthcare and service to us. During this journey, we transition from one setting to another, from one team to another, repeatedly. Communication knits this maze of actions, interactions, and transitions together. At its core communication is two or more people or parties sharing some information via some channel (voice, paper, digital, dramatic), one time or several times in a particular setting, hoping to accomplish something that moves us along in our health journey. One of the most persistent and ubiquitous frustrations in health care is that of poor communication. Poor communication at transitions is at the root of much overuse, underuse, and misuse of health resources, and results in the inability of patients to complete recommended treatment. For the patient and their family this means unnecessary delays in returning to health or worse. For those professionals on the care team the incidents of harm, burnout, stress, and frustration cause financial, emotional and career-ending consequences. Poor communication at transitions impacts each of the Quadruple Aims. The potential return for the investment in communication may cross over one or more organizational boundaries. Organization Boards and the C-Suite customarily focus on activities within their institutions, not between. The daunting nature of the challenge, caused by the shear volume and variety of transition nodes, can paralyze those in decision making roles, leading to smaller, more manageable local solutions. I support building a more holistic solution that includes the necessary governance, infrastructure, habits, and relationships. This leads to systematically applied common standards for local, node-specific solutions. Development should include all persons at the center of care in governance, design, operations and learning for systemic and local solutions. Refined clinical work flow should be constructed to respect patient and care partner life flow. Solutions should use interoperable technology to aid, not replace, communication. Transition information and processes should be transparent to patients and their care partners.

The Big Picture

The Quadruple Aim [1], a unifying goal for the health care industry, is being widely adopted across the full continuum of care. The Quadruple Aim includes:

- Improving the patient experience of care;
- Improving the health of populations;
- Reducing the per capita cost of health care; and
- Improving the work life of clinicians and staff.

Some say that striving towards a goal that can never be totally reached is folly. I believe that working towards the Quadruple

Aim represents an audaciousness needed to progress in solving our health care system's challenges.

Facing such a large challenge, some are tempted to ignore the opportunity completely, some continue to do that which they already do well, and others nibble at the problem. This essay is for the people who believe in the inadequacy of these responses.

Anecdotes abound indicating that our current health care system has far to go before approaching success in achieving the Quadruple Aim. Statistics are readily available—but we won't focus on them here; you may find or recall your own favorites! But here are two worth repeating:

- Approximately 30% to 50% of US adults are not adherent to long-term medications, leading to an estimated $100 billion in preventable costs annually [2].
- In 2011, there were approximately 3.3 million adult hospital readmissions in the United States associated with about $41.3 billion in hospital costs [3].

Where else inside of a modern organization can one witness such a wide range of people—from highly trained and specialized professionals to technical staff to housekeeping staff? Where else can you find such a high volume of patient (individual) interactions whose results can be life-or-death critical and may be time restricted to as little as 8 minutes? What industry is so complex that everyone finds part of it a complete mystery? What industry is projected to be the single largest segment of the US economy by 2024? Health care.

Health as a Journey

To be audacious and take significant steps toward achieving the Quadruple Aim, we patients and caregivers need to better understand key features of our health journeys. When on that health journey, we are patients interacting with a series of care teams: our home team (social network), our primary care team, our specialist team(s), our community agency teams, our emergency care team, our hospital teams, and on and on. These care teams include ourselves, our caregivers, clinicians, other professionals, and direct care and support staff—people at the center of care. The actions taken by people at the center of care to improve, maintain, or adapt to our health or illness represents our health care. Actions can be diagnostic, taking medications, undergoing procedures, learning, living life, and getting help living life. So, our health journey is teams of people at the center of care taking such actions to provide health care and service to us. During this journey, we transition from one setting to another, from one team to another, repeatedly. The adult child of an elderly woman describes their journey:

> I'm the child, custodian and health care proxy of my 89-year-old mother, Alice. I live in a different state. My mother has diabetes and is depressed. Her care team, beside herself and me, includes medical providers in various health settings, community support agencies, and a full-time caregiver who helps her schedule and get to health-related services. My problem is to understand what my mother wants for herself and to track who says they're doing something for her (including my mother and me), what they're

> doing, and when they're doing it. I want to know what it takes to do it (Can she afford it? Can she get there? Does it agree with her? Who will be with her? etc). I want to know if the actions have the effects we thought they would. I want to know what her risks are and how we plan to prevent or respond to them. I want to able to keep track of all this and keep it current. I want to share it or have it shared from day to day and from setting to setting even if I'm not present.

Communication at Transitions

Communication knits this maze of actions, interactions, and transitions together. At its core, communication is two or more people or parties sharing some information via some channel (voice, paper, digital, dramatic), one time or several times in a particular setting, hoping to accomplish something that moves us along in our health journey. One of the most persistent and ubiquitous frustrations in health care is that of poor communication.

These are some common complaints about communication, as expressed by real patients:

> I don't know when to call my doc or the hospital. What if I have new symptoms or questions about all these meds? Should I bother them on the weekend or at night?

> I see six specialists in three different systems, all with portals, and I'm still the person who schleps information from one doctor to the other.

> I was discharged after bypass surgery with 26 pages of instructions. I was just concerned about getting home.

Here, we are considering communication at transitions. Clinicians and patients, with their families, caregivers, and care partners, crave constant, collaborative, smooth, and sustainable communication during the health journey. Points of transition—where one person or group is being removed or added to the "team"—occur frequently and are the weakest link of communication in the care chain. I call these links "transition nodes." These nodes include clinician hand-offs (day-to-day and shift-to-shift); communication from one clinician to another (eg, between nurse and doctor, primary care to specialist, pharmacist to nurse); transfers from one level of care to another (eg, hospital to home, community health to primary care); and care planning between clinicians and patients and their support networks (eg, discharge planning from acute care or into or from home to doctor office). Health care communication across transition nodes happens billions of times a day with great cumulative impact on lives, communities, well-being, and resources.

Poor communication at transitions is at the root of much overuse, underuse, and misuse of health resources, and results in the inability of patients to complete recommended treatment. For the patient and their family this means unnecessary delays in returning to health or worse. For those professionals on the care team the incidents of harm, burnout, stress, and frustration cause

financial, emotional and career-ending consequences. Poor communication at transitions impacts each of the Quadruple Aims.

What We Have Observed

The content, manner, and place of transition of care communication vary widely. The effectiveness of transition communication decreases as the difference between professions, departments, systems, and levels of care increases (nurse shift-to-shift strongest, across departments weaker, across systems and from acute or clinic to community based or home is weakest).

Communication at shift hand-offs between nurses can vary depending on age and experience of the nurses, their team dynamics, acuity and diagnoses of the patients. Thirty-year-old clinicians may communicate differently than 60-year-old clinicians. Intensive care unit (ICU) professionals share different information than emergency department (ED) professionals. And for all clinicians, there is a wide range in the degree of comfort about when to include patients and their families in discharge and care planning.

In general, a tension exists between the wealth of transition information needing to be communicated and the time needed to create, share, absorb, and understand that information. Acute care and clinic settings have the most time constraints. Chronic care and non-acute settings have more time, hence more opportunity for relationship building and person-centered information. Unfortunately, it seems that many organizations and teams only allocate adequate resources for improving transition communication after pain points have been reached or are threatened (harm, lawsuits, financial loss, public attention, and complaints) rather than proactively and systematically. Financial pressure to keep labor expense per patient as low as possible impacts effective communication.

Current Efforts

Many tools and mnemonics exist to aid in the consistency of transition communication. Mnemonics, a memory device used to standardize and train many people during frequent encounters, are each designed for a specific setting/node of communication. A limited number have evidence as to their effectiveness [4]. Most contain identifying information, summary and current state, immediate plan, current or anticipated risk, and opportunity for learning (questions and synthesis).

Current published transition communication tools are predominantly acute care and medicine-centric [5]. Yet, transitions occur across the health continuum and with all members of the health team (licensed and non-licensed, professional and non-professional). Membership of a person's health team can include the patient, their family and care partners, pharmacists, integrated health practitioners (chiropractors, massage therapists, nutritionists, etc), and community health agencies. Transitions increasingly occur outside of the hospital and traditional medical clinics, in settings such as mobile health, community and home, and retail walk-in and urgent care centers. In fact, such transitions increasingly include social services such as criminal justice, employment, housing, education, and child services. This is the extended continuum of care.

Organizations cited as exemplary in transition communication excel in one or maybe two nodes of transition. Technology could help, yet existing electronic health records are seldom interoperable or easily accessible at time of transition by all stakeholders. Hence, much communication still occurs on paper, via fax, by voice, or telephone. Too often the patient provides substantially all the communication and coordination.

Solutions

Meeting the audacious goal of achieving the Quadruple Aim through collaborative, smooth, sustainable, and effective communication at all transition nodes in the health journey requires an infrastructure for implementing sustainable change to achieve success. This transition of care communication infrastructure includes patient and caregiver engagement, policies and standards, workforce management, technology, work flow and life flow, governance, and learning (see Textbox 1).

Sustainable implementation of transition communication can be tool agnostic. Building the infrastructure is an iterative, growing, learning endeavor with common system and leadership requirements. Designing the work flows and tools for specific transition nodes has unique local, operational components depending on the participants, the setting, and the culture.

Standards do exist for building and sustaining effective transition communication and communication tools. One example is the Joint Commission's SHARE Solutions that provides an approach for developing and evaluating hand-off tools (see Textbox 2) [6]. In addition, care planning has generally accepted components (see Textbox 3).

Establish standards for transition plans—create each plan with all parties involved including family and personal care partners and destination facilities. Document those plans with communication channels suitable to the users, lay and professional. Such standards could address a wide range of communication barriers, from external barriers like distinct electronic systems to internal barriers like age-related communication issues.

Some hospitals and clinics implement interactive voice response (IVR) calls and multimedia programs for transition communication.

Finally, the only consistency across transition nodes is the patient and their family and personal care partners, yet the industry is only beginning to include them in communication planning, work flow, learning, and technology. The Institute of Medicine (IOM) recommends that patients become a full partner in their own care. Patients can be an important safety net in catching errors before they lead to harm.

Textbox 1. Transition communication infrastructure.

Patient and Caregiver Engagement: Patients and caregivers participating in design, operations, governance, and learning.

Policies and Standards: Play-book or standard approach for the key elements of information, data, tracking, and work flow regarding communication in each node setting.

Workforce: All people at the center of care and their leaders hired for, aligned, and committed to collaborative, smooth, sustainable transition communication every time.

Technology: All electronic communication vehicles and channels (such as, EHR, portals, web sites, messaging, phones, faxes) synchronized and interoperable to support transition communication and care planning.

Work flow: Clinician, direct care, and support staff work processes proactively designed for efficient and effective communication at all nodes.

Life flow: Clinicians, direct care and support staff appreciate the complexity and context of patient and caregiver lives as they manage health away from professionals.

Governance: Explicit accountabilities for transition communication at each node and overall with resources allocated to support.

Learning: Standardized orientation and continuing education of all transition dyads within and across professions, departments, and organizations. Routine measurement and analysis of transition communication effectiveness with sharing of lessons learned to all stakeholders.

Textbox 2. The Joint Commission Center for Transforming Healthcare's SHARE Solutions [6].

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1. **S**tandardize critical content.

2. **H**ardwire within your system.

3. **A**llow opportunity to ask questions.

4. **R**einforce quality and measurement.

5. **E**ducate and coach.

Textbox 3. Care planning components.

- What needs to happen?
- By whom, by when?
- Goals/Expected outcomes?
- Anticipated risks and amelioration strategies
- Barriers

Communication usually occurs in dyads—a dynamic of two individuals or two teams (nurse-nurse, patient-doctor, hospital-nursing home, etc). Each individual or team in the dyad can have widely varied comfort and skill in that communication. That variation occurs for clinicians, support staff, patients, families, and site of care. Individuals and teams need to take their dyad partner where they are and persistently increase comfort and skill. This means first, understand the stages of skill and comfort (engagement, activation, background, experience), next quickly assess your dyad partner's stage, and then fine-tune the communication to that assessment. All this requires learning and continuous improvement: orientation, training, continuing education, coaching, process and outcome measurement, and work flow refinement.

Final Thoughts

The Quadruple Aim can be significantly accelerated by effective communication at transitions. Why don't health care organizations invest more in comprehensive, sustainable solutions? I believe the potential return for the investment in communication may cross over one or more organizational boundaries. Organization boards and the C-suite customarily focus on activities within their institutions, not between. The daunting nature of the challenge, caused by the shear volume and variety of transition nodes, can paralyze those in decision making roles, leading to smaller, more manageable local solutions.

I support building a more holistic solution that includes the necessary governance, infrastructure, habits, and relationships. This leads to systematically applied common standards for local, node-specific solutions. Development should include all persons at the center of care in governance, design, operations and learning for systemic and local solutions. Refined clinical work flow should be constructed to respect patient and care partner life flow. Solutions should use interoperable technology to aid, not replace, communication. Transition information and processes should be transparent to patients and their care partners.

Critical to success:

1. Board and C-suite *prioritize*
2. All levels of management *accountable*

3. People at the center of care *included* at every step
4. Persistently and continually *improve and apply lessons learned*
5. Emphasize *transparency of information and processes* to all stakeholders.

As a patient or caregiver, you can make a difference.

1. When you are well enough and have space in your life, *get a seat at the table*. Pick a table that suits you. You may have had an unsettling or delightful experience at a hospital, clinic, agency—any setting. You may be good at governance, design, publicity—you know what you are good at. Speak with the boss—the Executive Director, CEO, chief physician. Ask to join the board, the Patient Advisory Committee, wherever decisions are made.

2. Pay attention to communication at transitions. Ask to shadow people at the center of care. Ask questions. See where communication works and where it doesn't. Put the topic on the agenda and share what you've learned.

3. When you are a caregiver of a patient in a hospital or going to the doctor or moving along a health journey, pay close attention to communication at transitions. Who is communicating with whom? How is the patient involved; how are you involved? Ask questions. Find out who to contact when you leave that setting. Expect a name, number, or link. Questions always come up even if you record everything.

You're on your way! It's worth it for patient experience, clinician well-being, population health, and every bottom line.

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Case Studies, Evidence

Evolving Patient-Researcher Collaboration: An Illustrative Case Study of a Patient-Led Knowledge Translation Event

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Abstract

Patient engagement occurs when patients actively collaborate in health research in ways that are meaningful to them. Resources to facilitate patient engagement have been developed, but their approach is mainly toward building competencies in the early stages of forming new practices of patient engagement. This paper describes a patient-led collaboration in rheumatology, in the context of an established patient-researcher partnership. Using a case study approach, we report on a research knowledge translation event, titled eROAR2013 (Reaching Out with Arthritis Research), led by members of the Arthritis Patient Advisory Board (APAB), which is a group of volunteer advocates living with arthritis based at Arthritis Research Canada. We provide an overview of APAB's decade-long history, describe the planning and the event itself, and report on the challenges encountered, reflections and solutions pertinent for sustaining patient-researcher collaborative practices.

Introduction

The motto "Nothing About Us Without Us" underpins patient engagement in health research [1]. Adopted by the global disability rights movement, it reflects the principle of participation and wider societal developments toward realizing citizen empowerment [2,3]. Similarly, the emergence of "patients as partners" is integral to patient-centred care and shared decision making [4,5,6]. These developments, underpinned by values and ethical concepts such as mutual respect, have laid a foundation for patient engagement in health research.

Patient engagement in research varies from minimal involvement to more participatory collaboration, and is broadly understood to occur when patients meaningfully and actively collaborate at any stage of the research process, from setting the research agenda to designing the research project, collecting data, and disseminating results [7,8,9,10]. Support for patient engagement continues to increase [1,7,11]. For example, research funding agencies in Canada, the United States (US), United Kingdom (UK) and elsewhere recommend patient engagement as a means

to improve research relevance and quality [8,12,13]. Yet, despite the strong rationale for patient engagement in research [11], the process of patient-researcher collaboration is little understood [14,15]. The UK's National Institute for Health Research national advisory group INVOLVE have provided guidance to researchers to plan public involvement in research [16]. Hewlett and colleagues have also suggested a framework for patient-research partners based on experiences of researchers and patients collaborating in rheumatology research in the UK. They describe practical aspects and identify challenges (eg, anxieties felt by patient partners taking on a new role) [15]. While these publications can guide efforts to begin cultivating patient engagement in research, examples of collaboration in established patient-researcher partnerships of engagement in research are scant.

In this paper we describe a patient-led collaboration in rheumatology, embedded in an established patient-researcher partnership of over 10 years. We report on a research knowledge translation event, titled eROAR2013 (Reaching Out with Arthritis Research), as an illustrative case study of patient engagement in research [17]. While the event illustrates patient engagement in the late stages of the research process, it builds

on patient-researcher collaboration from study inception. eROAR2013 also presents an example of the dynamic process of research knowledge translation, which aims to reach stakeholders at all levels of the health system (eg, patients, the public, and health practitioners) to make research evidence for informing health decisions accessible [18].

The patient collaborators were members of the Arthritis Patient Advisory Board (APAB) [a], based at Arthritis Research Canada where the researcher collaborators are also based. We describe the role and development of APAB and report on the planning, preparation, and description of the event. Finally, we outline the challenges to emerge, report our reflections and suggest solutions in the collaborative process.

The History of the Arthritis Patient Advisory Board (APAB)

APAB [a] is comprised of volunteer advocates with at least one form of arthritis who bring personal experience and arthritis knowledge to research decision making at Arthritis Research Canada [19]. APAB was created in 2001 as a patient representative body of Arthritis Research Canada (created in 2000) with a mission "to participate in all components and phases of arthritis research, and serve as a bridge between researchers, people with arthritis, and the community at large" [20]. Established with five members, APAB included 15 current members and nine alumni (19 women; 5 men) in 2013. [b]

Alumni periodically provided knowledge, expertise and advice to support the current members, whose roles included, but were not limited to, identifying research topics, shaping the research design, participating in grant applications, co-authoring scientific papers, and attending conferences, as well as mentoring other APAB members, researchers, trainees, and research staff at Arthritis Research Canada.

Since 2006, APAB members have organized annual knowledge translation events called Reaching Out with Arthritis Research (ROAR) in Vancouver, Canada, for people affected by arthritis. Each interactive event includes presentations from patients, researchers and health professionals providing practical information linking research to best practices in the prevention and management of arthritis in everyday life. This event also seeks to identify patients' research interests by encouraging dialogue between patients and researchers, enabling opportunity for patients perspectives on research to be prioritized and incorporated in future patient-oriented research at Arthritis Research Canada. Participants are invited to an event via word of mouth, advertisements posted in local community centres and newspapers, as well as notices circulated online via social networking sites (eg, Facebook, Twitter), APAB's quarterly newsletter, email distribution lists and newsletters of national organizations (eg, Arthritis Alliance of Canada, Arthritis Consumer Experts, and Canadian Arthritis Patient Alliance. Originally an in-person only event, since 2012, electronic media has extended the reach to a national and international audience of approximately 200 participants in total (Figure 1). [c]

Figure 1. A History of ROAR's reach

Year	Title	Audience Size		
		In-Person	**Webcast**	**Twitter**
2006	Taking it to the Street	150-175	N/A	N/A
2007	Roundtable on Arthritis Research	Unavailable	N/A	N/A
2008	Learning and Living to the Limit	200-225	N/A	N/A
2009	Learning and Living to the Limit	100-125	N/A	N/A
2010	Arthritis Research for Everyday Living	Unavailable	N/A	N/A
2011	Arthritis Research for Everyday Living	150-175	N/A	N/A
2012	Arthritis – Active for Life	125-150	75-100	Unavailable
May 2013	Don't Let Your Arthritis Kill You – Take Action	50-75	100-125	Unavailable
Nov 2013	eROAR2013: Does a Google a Day Keep the Doctor Away?	50-75	75-100	100-125

In July 2013, APAB co-chair SK initiated a patient-researcher collaboration to raise awareness of preliminary findings from an ongoing research project titled "Exploring E-health Ethics & Multi-Morbidity" through a ROAR event [21,22]. Funded by a Canadian Institutes of Health Research (CIHR) catalyst grant competition (EPP-122907) in October 2012, the "Exploring E-health Ethics & Multi-Morbidity" project involved a transdisciplinary team with expertise in health services, rehabilitation, ethics and medical sociology, as well as health professionals, two patients and educators, led by AT and CB. APAB co-chair SK had acted as one of two patient collaborators

on the project since its inception, providing perspectives that shaped the research topic and design.

Planning and Preparation

Building on the well-established partnership with researchers at Arthritis Research Canada and drawing on their experience in hosting previous ROAR events, APAB collaborators were co-leaders in planning a ROAR event titled "eROAR2013: Does a Google a Day Keep the Doctor Away?" between August-November 2013. In September 2013, AT and JL were invited to attend one of APAB's monthly meetings for its

members (totalling 15 at the time). These structured yet informal monthly meetings routinely opened with a hot meal and "catching up," which contributed to a culture of caring and respect for each other's well-being, welcoming guests, and acknowledging individuals as members of the collective team. Following this, AT and JL described the research project "Exploring Ehealth Ethics & Multi-Morbidity" [21,22]. Of the total APAB membership (15 in 2013), approximately 10 were in attendance (either in-person or by phone) at the meeting with AT and JL to discuss how to ensure central concepts and messages from the research project would be accessible and meaningful to lay audiences. APAB's co-chair SK played an invaluable lead role in enabling voices to be heard. APAB members combined their patient and collaborator roles and identities rather than compartmentalizing them, opening a participatory space for talk around living with arthritis and research tasks, bringing a richness and sensitivity to the discussions. Early in this planning process it was apparent that APAB's culture and researchers' interests aligned and fostered a participatory process underpinned by mutual respect for each other's roles. By creating this informal, inclusive and interactive environment, decision making was a collaborative process from the beginning. Consistent with published frameworks, these elements illustrated a collaboration based on shared understanding and a recognition of multiple identities within the life contexts of APAB members [15].

SK and AT acted as representatives for APAB and the research team respectively. The aims and format of eROAR2013 were agreed upon and clearly laid out in the early stages of planning, which required dialogue and precise understanding between all parties (i.e. APAB members and the research team). Mutual agreement on strategies of communication for the event was also required. APAB collaborators led the preparation and dissemination of promotional materials for the event, including the level of language used, format and key distribution channels. There was an ongoing negotiation via emails between SK and AT with final promotional materials approved by APAB members. The range of speakers and the event's interactive format was also agreed upon (eg a balance was agreed on the level of interaction versus the number and range of speakers at the event) based on listening to each other's perspectives. To reach these agreements, SK and AT communicated via regular emails and feedback to APAB members (during monthly meetings) and the research team (during bi-weekly in-person progress meetings) respectively. SK and AT also held separate in-person meetings a minimum of once a month and corresponded regularly by email and phone.

APAB members contributed organizational, leadership, communication and other skills and resources to the planning process, which were relied upon by the researchers. For example, a committee of five APAB members led by SK set key milestones and oversaw progress to achieving them. The committee independently secured the event venue, and requested EC (employed by APAB as a Research Liaison with funding allocated by Arthritis Research Canada) to arrange webcasting services for the event. One APAB member with an employment background in marketing endorsed a graphic illustrator (proposed by AT and JL) to do live visual note-taking of the session (see Figure 2).

Figure 2. Visual note-taking of the session

Visual Note-taking by Sam Bradd

Another APAB member (who was also a physiotherapist) prepared stretch breaks, and another member (who was also a professional actor) worked with AT on the analysis of research data to present findings as a role-play [23]. Also led by SK, a separate committee of two APAB members developed the event's budget, including allocating funds from APAB's budget, and a smaller amount from the research grant co-led by AT and CB [21,22]. Furthermore, SK recruited APAB members to provide feedback on presenters' slides for clarity and lay language in advance, organize catering, set up the venue and audio-visual equipment, or present or co-present on the day of the event.

Collaborators also held a teleconference to invite AM, a patient advocate/activist living with arthritis to moderate online conversations about the event, on account of her expertise in engaging with healthcare stakeholders using social media and her existing online network. Based in Toronto, AM advised on how to create an appropriate hashtag, generate interest on Twitter in advance of the event to maximize the number of online attendees on the day, and use social media analytics to assess the impact of the event. AM also prepared content to stimulate social media discussion about the event in advance and during the presentations. Thus, patient leaders drove the planning process of the event, anticipating how to engage with

audiences, and contributing a range of valuable resources, skills and expertise, which researchers may not otherwise have had access to. These contributions were sincerely valued within the patient-researcher collaboration, which strengthened mutual respect for each other's roles and priorities throughout the planning and preparation phase.

The Event

APAB members and researchers worked together during the event to stimulate interaction between local, national and international stakeholders via multiple methods of engagement. While both patient and researcher collaborators were on-hand to greet the 52 in-person audience members, EC moderated a live webcast that reached 117 total views (7% from outside Canada) and, as the online facilitator, AM stimulated a conversation on Twitter involving 42 participants (62% from outside Canada). APAB collaborators also supported CB whose role it was to include online participants in the in-person conversation. Of the six presentations, three were given by APAB members and a patient (who subsequently joined APAB) with expertise in social media, who shared their first-hand knowledge on Internet health resources, apps, devices and games, and online support groups (Figure 3) [24,25].

Figure 3. Topics and speakers for eROAR2013

Topic	Speaker
Informed or Overwhelmed? The Patients' View of Internet Health Resources, Apps, Devices and Games	**Sharan Rai** APAB Member **Alison Hoens** APAB Member Physiotherapist Physical Therapy Knowledge Translation Broker, UBC
Ethics in the Age of E-health	**Professor Emeritus Michael McDonald** W. Maurice Young Centre for Applied Ethics
A Patients' View of Using Social Media	**Kelly English** Arthritis Patient
Break	
Burdens and Benefits of Using E-Health: Focus Group Study Results	**Dr. Anne Townsend** Research Associate, Department of Occupational Science and Occupational Therapy, UBC Affiliate Scientist, Arthritis Research Canada **Marilyn Mulldoon** APAB Member
The Arthritis Health Journal: An Online Tool to Promote Involvement of RA Patients in Their Care	**Dr. Diane Lacaille** Rheumatologist Arthritis Research Canada Research Scientist Professor, Division of Rheumatology, UBC
Using E-health with Patients	**Dr. Eric Cadesky** Family Physician Clinical Instructor, Faculty of Medicine, UBC

In turn, the patient priorities were emphasised as potential areas of future research. An ethicist, a clinician scientist, and a family physician also gave presentations and discussed research relevant to the theme of the event, positioned as experts alongside the patient expertise (Figure 3) [23,26,27]. In these ways, the choice of speakers and presentation topics illustrated

a break with the traditional hierarchy of scientific knowledge and patient or lay experience. APAB and researchers were able to work together to develop an inclusive, accessible and engaging event in which different perspectives and various forms of knowledge (eg experiential, scientific) were mutually welcomed and exchanged.

Challenges, Reflections, Solutions

One challenge for patients and researchers was negotiating the patient-led aspect of eROAR2013 and the associated effort this meant (while acknowledging potential burdens for patients). Given the wide range of experience and skills of the APAB members, those less-experienced felt uncertainty about the tasks they undertook and sought guidance and support from other more experienced patient collaborators and researchers. A respectful approach taken by patient and researcher collaborators recognized this diversity within APAB members, in their specialist skills, knowledge and varying degrees of experiences, as well as different life situations and stages of illness, which impacted the nature and level of their engagement. In addition to balancing expectations of APAB members' roles and responsibilities in the context of daily lives, it would be helpful for more experienced patient and researcher collaborators to provide more induction, mentorship and training to less experienced APAB members.

Challenges also emerged in the collaborative decision making process, for example in the event planning. In order to reach an agreed balance between academic terminology and every-day language to promote the event, the collaborators spent significant time in discussion, working together in a joint intellectual effort [28]. This process meant delays to the scheduled release of promotional materials, and contributed additional unanticipated hours that had not been bracketed into already busy schedules (eg involving work, managing health, travel and other daily life contingencies). Also, both APAB and researcher collaborators found it challenging to clarify the expectations and responsibilities of the remote patient's role because it was unprecedented at a ROAR event. To prepare for moderating the conversation on Twitter, AM independently sourced a significant amount of information. It was particularly difficult to predict in advance how much time would be required to perform this role, and to plan ongoing support effectively. One potential solution could be for collaborators to develop a guide to simplify the steps involved in hosting a chat on Twitter in advance, covering details such as registration of the hashtag (#eROAR13), publicity, and receiving presenter slides in a timely manner.

APAB collaborators reflected that they valued learning about the latest arthritis research during discussions, while researchers valued the training they received from APAB collaborators on how to better engage lay audiences with their research, the specialist skills and expertise they provided and the insights into their experience of collaborating in the context of their daily lives. This recognition and appreciation for mutual learning and respect built on the established research partnership, and made reflecting on the challenges more comfortable. In this way, trust and respect underpinned collaborative decision making that recognised differences in expertise, skills, experiences and priorities. By perceiving patient collaborators as experts in their own right, rather than experts in the researchers' own image (whereby training may be needed for patients to conduct research), the more traditional hierarchy of knowledge was dampened. In its place was a mutual appreciation of the diverse skills that drove the collaboration, which in this instance was a patient led KT event that encapsulated the concept of "Nothing About Us Without Us" in principle and in practice.

The case study we report offers an opportunity to expand on the fledgling practice of patient engagement often reported in existing literature, such as that of INVOLVE and Hewlett [15].

It was a cooperative experience that can contribute to refining our thinking and enactment of patient engagement as it develops in the context of established patient-researcher partnerships [16].

Conclusions

Building successful, effective and meaningful patient engagement in research is a multi-layered, sometimes challenging, and valuable process that continues to evolve. In a knowledge translation event held in Vancouver, Canada, strong relationships built over time laid the foundation for a patient-led collaboration that revealed a different type of patient engagement than is typically reported. In describing the responsibilities and practical tasks undertaken, values and ethical considerations (eg, mutuality, understanding, respect and diversity) that underpin patient engagement in research are revealed as they are enacted relationally in a participatory space. It is our hope that this paper will help others to reflect on the changing nature of patient-researcher collaboration. We welcome feedback on our description and reflections on this case study.

Conflicts of Interest

The authors have declared that no competing interests exist.

Endnotes

a Formerly known as the Consumer Advisory Board, the Arthritis Patient Advisory Board chose to change its name in 2014 as it was felt the term "consumer" denoted an individual who purchased information or health care by choice. Members felt more

comfortable identifying with the term "arthritis patient," as it was considered to be more accurate while no longer seeming to indicate passivity as it had done when the original name was chosen.

b At the time of writing, APAB includes 23 members and 12 alumni. (29 women; 6 men).

c Figure 1 includes data up to and including the eROAR13 event. Further information about ROAR events (including those after 2013) is archived on Arthritis Research Canada's website at www.arthritisresearch.ca.

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Evidence, Research

The Effects of Coaching Patients to List Questions Before Visiting Cancer Specialists: Retrospective Evaluation of Visit Preparation in a Rural, Underserved Setting

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Abstract

Background: A community-based organization implemented an evidence-based intervention to help rural cancer patients list questions before oncology visits.

Objective: Was the question-listing intervention effective in reducing anxiety and increasing decision self-efficacy?

Methods: The organization surveyed patients on decision self-efficacy (273 respondents, 99% response rate) and anxiety (190, 68%) before and after question-listing interventions delivered from 2006 – 2011. We analyzed responses using two-sided paired t-tests at 5% significance and conducted linear regression to identify significant predictors of change. We examined predictors related to the patient (location, demographics, disease status and baseline decision self-efficacy and anxiety); the intervention (including interventionist case volume); and the visit (including type of doctor seen).

Results: Question-listing was associated with higher mean decision self-efficacy (2.70/3.43 pre/post, 1-4 min-max, *P*<.001) and lower mean anxiety (7.26/5.87, 1-10 min-max, *P*<.001). Significant predictors of change in decision self-efficacy included: patient location; interventionist case volume; baseline decision self-efficacy and anxiety. Higher baseline anxiety was also associated with reductions in anxiety.

Conclusions: In a sustained community-based implementation, the intervention helped patients prepare for oncology visits. Patients reported higher self-efficacy and lower anxiety.

Introduction

People facing cancer are known to experience communication barriers that impede their ability to address their information needs with their most trusted sources of information, namely their physicians [1,2,3]. Researchers have proposed various approaches to helping patients prepare for medical visits in order to overcome these barriers and obtain personalized information. These interventions were summarized in a recent systematic review [4]. For example, Cegala and colleagues developed a comprehensive model (PACE) that teaches the patient to provide information, ask questions, check or clarify understanding, and express concerns. A common theme across such visit preparation interventions is the importance of helping patients ask questions. Roter, Butow, Cegala, and colleagues have documented that having a written list of questions is associated with an increase in the number and range of questions that patients ask [1,4,5,6,7], with minimal or no harm [1,8,9,10].

Based on this evidence, one of the authors (JB) developed a process for coaching patients to identify and write down questions for upcoming visits with specialists [11]. An evaluation found the question-listing intervention efficacious [12], and researchers implemented it at the University of California, San Francisco (UCSF) breast care center [13,14], where it has been sustained by internal and external funds since 1998 [15,16]. The intervention has spread to other urban or academic settings, where it has been associated with an increase in decision self-efficacy [13,17,18,19], i.e. patient confidence about making decisions with providers [20].

In 1998, a rural patient support organization in Northern California adopted question-listing based on a recommendation from a nurse who moved from urban Palo Alto to rural Mendocino, CA. This community-based organization, known as the Cancer Resource Centers of Mendocino County (hereafter, the resource center), attended annual training at UCSF starting in 2000. [21] In 2003 the resource center embarked on a community-based participatory research program with UCSF to adapt, expand, and evaluate its question-listing service. In our initial evaluation, we found high levels of satisfaction among the existing clientele of the resource center, [22] and successfully adapted the intervention to the needs of the diverse, rural population [23], including delivery by telephone [17].

Since 2006, the resource center routinely collects responses from all patients to decision self-efficacy and anxiety surveys before and after the question-listing intervention. Therefore, in 2012 the Executive Director (author SO) suggested analyzing all these surveys to learn about effects on anxiety as well as decision self-efficacy.

The authors believed this presented a good opportunity to evaluate the effects on psychosocial outcomes of an intervention implemented in a rural, medically underserved community setting. University researchers (authors JB, MN, LS, JW, and SV) joined forces with the resource center (author SO) to review program records over a five-year period (2006-2011). We asked the following questions:

1. Was the question-listing intervention associated with changes in decisional self-efficacy and anxiety?
2. Did changes in decision self-efficacy and anxiety vary across subsets, including patients who did not have breast cancer?
3. Were there any significant predictors of variation in decision self-efficacy and anxiety?

Methods

Decision Self-Efficacy (DSE)

Notice that the first subheading immediately follows the last heading. Subheadings under subheadings are also possible (see Statistical Analysis).

Anxiety

The resource center measured anxiety using a single item, administered at the same time as the decision self-efficacy scale. The item measures anxiety on a scale of 1-10 by asking respondents to complete the statement "On a scale of 1-10 (1 being the lowest, 10 being the highest), my anxiety level is…" The resource center used a single item to minimize patient burden as was done in two prior studies [24,25] where a single item was found to be an acceptable substitute for a longer standardized scale. The rationale for measuring anxiety was the evidence that reducing the immediate anxiety and distress surrounding a cancer diagnosis can positively influence the patient's trajectory through treatment and survivorship, including pain and fatigue, quality of life (bodily pain, physical function), treatment adherence, future cancer surveillance, health behaviors (e.g., exercise), self-care (e.g., managing lymphedema), immune function, and recurrence and survival [26-32]. As with decision self-efficacy, resource center leaders felt that their organization's delivery of question-listing could directly influence anxiety as the first link in a longer causal chain, most of which was outside of their direct control.

Predictor variables

In addition to decision self-efficacy and anxiety, we abstracted from resource center records information about respondent demographics: Age (continuous), gender (male/female), ethnicity (white non-hispanic versus non-white), income (<= 250% of the federal income level versus >250%), location of first intervention (coastal versus inland office of the resource center); disease status (pre-cancer versus invasive cancer); and if diagnosed with invasive cancer, what stage (I-IV). We initially coded type of cancer into breast versus other, since our prior studies had focused exclusively on breast and we were curious about any differences versus all other cancers. We subsequently categorized type of cancer into 11 categories: breast, colorectal, digestive system, head and neck, hematologic, lung, ovarian, prostate, skin, urogenital, and other cancers. We captured service delivery characteristics including year of patients' first access to intervention (2006-2011) and whether the intervention was delivered over the telephone (yes or no). There were 12 resource center employees who administered the question-listing intervention in the study period. Interventionist characteristics included intervention volume since 2003 (a continuous variable reflecting the employee's experience administering the intervention) and whether the interventionist was a cancer survivor (yes or no). The interventionist characteristics were logically associated with each other and with location. The resource center was founded by cancer survivors, and so the longest-tenured and highest-volume interventionists were cancer survivors, and they worked in the inland office. Conversely, newer and lower-volume interventionists were not cancer survivors, and worked in the coastal office. We kept this multi-collinearity in mind when conducting our exploratory multivariable analyses. Finally, we gathered from program records information on the specialist type visited (medical oncologist, radiation oncologist, surgeon, other) and whether the specialist was local (local or non-local). See Figure 2.

Figure 2. Predictor variables for decision self-efficacy (DSE) and anxiety.
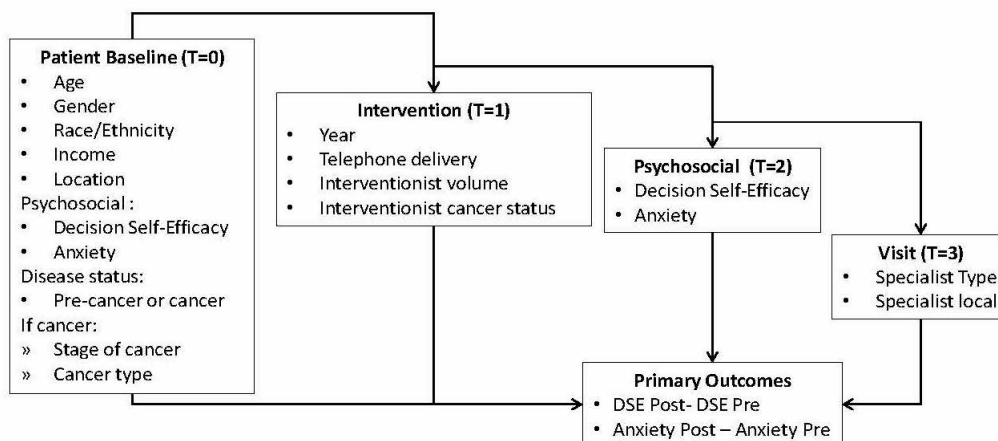
Intervention

with each other and with location. The resource center was founded by cancer survivors, and so the longest-tenured and highest-volume interventionists were cancer survivors, and they worked
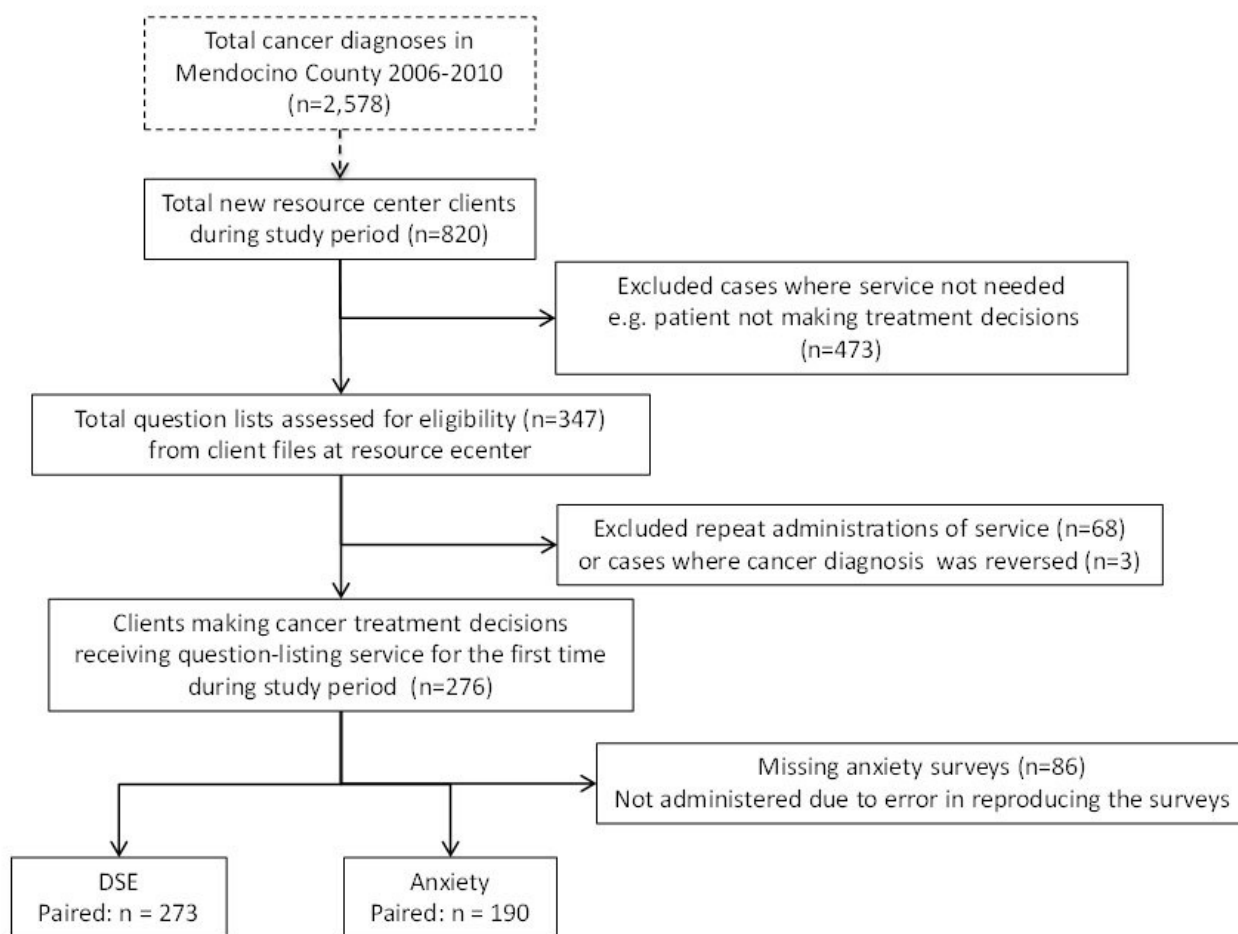
Question-Listing

Resource center employees routinely offer a question-listing intervention to clients with a cancer diagnosis who self-refer or are referred by health care professionals for community-based psychosocial support. The intervention consists of a structured interview in which the interventionist, a lay health worker, prompts a patient to articulate questions and concerns in preparation for a treatment discussion with a cancer specialist. The interventionist prepares a word-processed document paraphrasing and summarizing the patient's questions and concerns. The patient takes away the printed question list to serve as a visual aid and agenda during the meeting with the doctor. The prompts and an example question list are available online [33,34] and in the literature [13], where the intervention is referred to as Consultation Planning.

Interventionists

The resource center has two offices, one in Mendocino Village, on the coast, and the other in the town of Ukiah, inland. They are located an hour and half apart by car, and each location has its own staff. Assignment of the staff member who administered the question-listing service to clients was based on availability and proximity.

Data Collection Procedures

Following ethics approval from the UCSF committee on Human Research, author MN visited each resource center site and reviewed the paper files of every client that received question-listing. From these 347 files, author MN recorded demographic information obtained by the resource center upon patient registration at intake, and responses to the decision self-efficacy and anxiety questionnaires stored in the program records. This left us with 276 client files, 273 of whom had completed both pre and post surveys for decision self-efficacy (response rate = 99%), and 190 of whom had completed pre and post surveys for anxiety (response rate = 68%). See Figure 1. The surveys were collected immediately before and after the intervention by the interventionists.

Figure 1. Flow chart for creation of analytic sample.

Analysis Plan

Question 1: Was the Question-Listing Intervention Associated With Changes in Decisional Self-Efficacy and Anxiety?

We compared dotplots to examine whether the distributions of decision self-efficacy and anxiety had shifted; and scatterplots to examine the changes on a paired (pre/post) basis. We used the binomial sign test to test the null hypothesis of responses being as likely to go up or down, at a significance level of 5%. We used two-sided paired t-tests to compare, at a significance level of 5%, the overall pre and post mean decision self-efficacy and anxiety scores. We used a published algorithm to calculate Cohen's d for paired data [35], adjusting for the correlation between pre and post scores.

Question 2: Did Changes in Decision Self-Efficacy and Anxiety Vary Across Subsets, Including Patients Who Did not Have Breast Cancer?

For binary and other categorical variables, we tabulated and compared the mean change scores within each subset level, using a paired t-test of the null hypothesis of no change at a significance level of 0.05. This helped us understand variation across subsets. To further assess predictors of variation, we conducted simple linear regression to assess whether each categorical or continuous predictor was significantly associated

in linear fashion with either decision self-efficacy or anxiety change scores, testing whether the coefficient was significantly different from zero at a significance level of 0.05. Here and elsewhere, we did not correct for multiple significance tests, as we considered these analyses descriptive and exploratory.

Question 3: Were There Any Significant Predictors of Variation in Decision Self-Efficacy and Anxiety?

From our simple linear regression results, we selected the predictors with a p-value less than 0.05. We entered all these into a multivariable linear regression model, then iteratively removed the least significant predictor, until we had a parsimonious model. We interpreted our multivariable regression results as exploratory and used them to refine hypotheses and measurement strategies for future studies.

Results

Sample characteristics

Our survey respondents were majority female (76%), in part because 50% of the clients overall had breast cancer. Most (89%) were white, non-Hispanic. Many (39%) were low-income (under 2.5 times the federal poverty level). Clients ranged from 26 to 91 in age, with a mean and median of 60. Eighty-six clients did not answer the anxiety question. This was due to an error in reproducing the paper surveys. The non-respondents to

anxiety resembled respondents in terms of key demographics (83% female, 92% white, 34% low-income).

Question 1: Was the Question-Listing Intervention Associated With Changes in Decisional Self-Efficacy and Anxiety?

Dotplot graphs of the decision self-efficacy pre (Figure 3 a) and post (Figure 3 b) show an upward shift in the distribution, reflecting improvement. A scatterplot (Figure 3 c) reveals that on a paired basis, most decision self-efficacy scores went up (221 out of 273, or 81%) while 32/273 stayed the same (12%) and 20 out of 273 scores (7%) went down. This is significantly different from the null hypothesis of an equal number of scores going up or down (sign test $P<.001$). The decision self-efficacy scale performed well in terms of psychometrics in this sample: we calculated a value of 0.96 for Cronbach's alpha for the pre-intervention responses to Decision Self-Efficacy. Cronbach's alpha was 0.93 for the post-intervention responses [36].

Dotplot graphs of anxiety responses pre (Figure 4 a) and post (Figure 4 b) show a downward shift in the distribution, reflecting improvement. A scatterplot (Figure 4 c) reveals that 136 out of 190 (72%) anxiety scores went down, 49 (26%) stayed the same, and only 5 (2%) went up. This is significantly different from the null hypothesis of an equal number of scores going up or down (sign test $P<.001$).

The overall mean decision self-efficacy score rose from 2.70 pre to 3.43 post, an increase of 0.73, which translated to an effect size (Cohen's d) of 1.04 [35]. A two-sided paired t-test with alpha 0.05 shows this increase is significant ($P<.001$) and the 95% confidence interval for the change was 0.65 to 0.82. The mean anxiety dropped from 7.27 pre to 5.87 post, a decrease of 1.40, which translated to an effect size (Cohen's d) of 1.00. A two-sided paired t-test with alpha 0.05 shows this decrease was significant ($P<.001$) and the 95% confidence interval for the change was -1.60 to -1.20. The question-listing intervention was associated with a consistent and large effect on the patients.

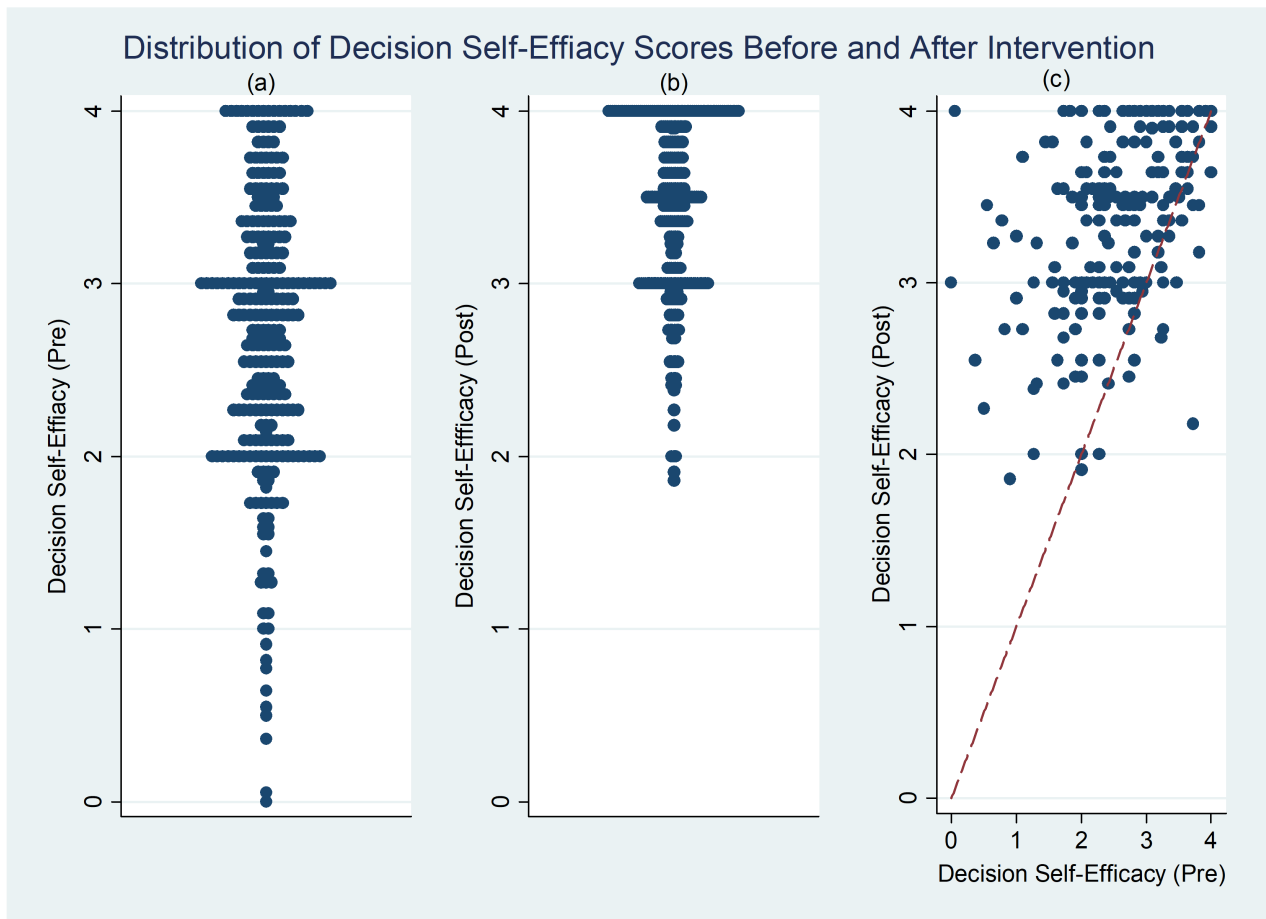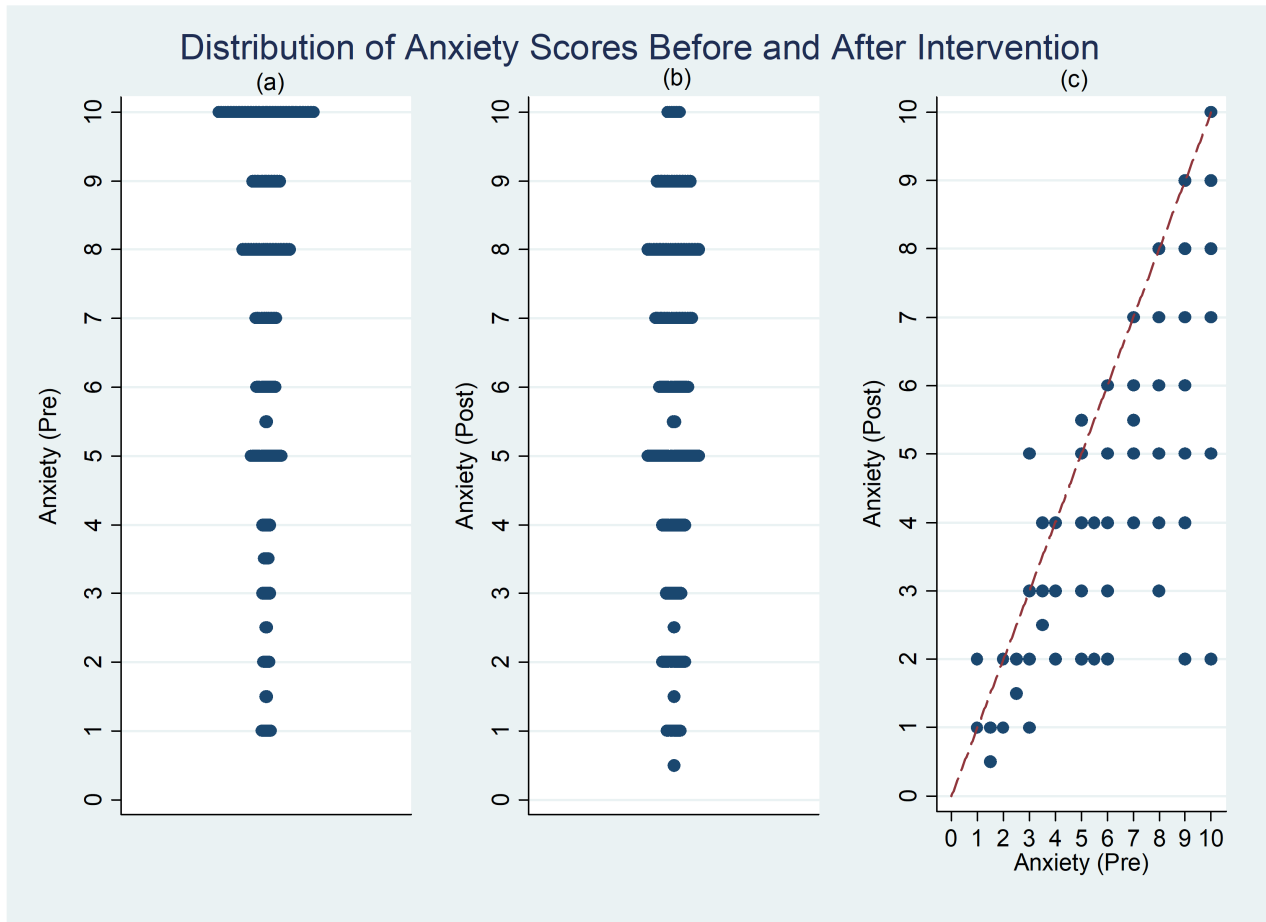**Figure 3.** Distribution of decision self-efficacy scores before and after intervention.

Distribution of Decision Self-Effiacy Scores Before and After Intervention

Figure 4. Distribution of anxiety scores before and after intervention.

Question 2: Did Changes in Decision Self-Efficacy and Anxiety Vary Across Subsets, Including Patients Who Did not Have Breast Cancer?

Figure 5 shows the results for subsets defined by dichotomous predictor variables. Discussed below are the multi-category variables (stage and type of cancer, interventionist, and type of specialist consulted) and the continuous variables (age, year and interventionist volume). We found that mean decision self-efficacy increased and anxiety decreased significantly from pre to post in all of the subsets defined by our dichotomous variables.

For the subsets defined by multi-category variables, regarding the outcome of change in decision self-efficacy, we found that interventionist and cancer stage were significant predictors, while type of cancer and type of specialist were not. For anxiety, among the multi-category variables, only interventionist was a significant predictor, meaning that the amount of anxiety reduction varied significantly according to which staff member delivered the question-listing intervention.

Using simple linear regression, we found that nine dichotomous predictors were significant predictors of change in decision self-efficacy. Among these, five had negative coefficients, meaning that an increase in the predictor would be associated with a decreased change in decision self-efficacy. Specifically, being more than 250% above the poverty level (versus below),

having breast cancer (versus other cancers), higher baseline decision self-efficacy, living in the Mendocino coastal region (versus inland Ukiah), and seeing a local (versus non-local) specialist were all associated with decreased change in decision self-efficacy (less improvement).

Conversely, higher baseline anxiety, receiving the intervention by telephone, or from an interventionist who was a cancer survivor or had a higher volume of experience, all were associated with larger gains in decision self-efficacy, and therefore predictive of greater improvement.

We found that six dichotomous predictors were significantly associated with the change scores for anxiety. Among these, three were negatively correlated, meaning that an increase in the predictor was associated with greater improvement (reductions) in anxiety. Specifically, higher anxiety, and receiving the intervention from an interventionist who was either a cancer survivor or had a higher volume of experience were all associated with greater improvements in anxiety. Conversely, increasing baseline decision self-efficacy, living in coastal Mendocino (versus Ukiah), and receiving the intervention by telephone were all associated with smaller improvements. See Figure 5 and Figure 6 (tabs 1 and 2)

Figure 5. Decision self-efficacy (DSE) and anxiety for subsets defined by dichotomous predictor variables.

Variable (N, % at baseline) [Percentages rounded]	Pre DSE mean	Post DSE mean	Post N	Mean DSE change (SD)	95% CI	Pre anxiety mean	Post anxiety mean	Post N	Mean anxiety change (SD)	95% CI
Patient status										
Gender										
Male (66, 24%)	2.52	3.32	66	0.81 (0.70)	(0.63, 0.98)	7.05	5.82	55	-1.28 (1.32)	(-1.64, -0.93)
Female (210, 76%)	2.76	3.47	207	0.71 (0.71)	(0.61, 0.81)	7.46	5.97	153	-1.48 (1.39)	(-1.70, -1.26)
Race/Ethnicity										
Non-White (28, 10%)	2.28	3.04	28	0.76 (0.77)	(0.46, 1.05)	8.48	7.13	23	-1.43 (1.34)	(-2.02, -0.85)
White, non-hisp (245, 89%)	2.75	3.48	242	0.74 (0.70)	(0.65, 0.82)	7.27	5.79	182	-1.46 (1.35)	(-1.66, -1.26)
Income (% poverty level)										
<=250% (107, 39%)	2.62	3.43	106	0.82 (0.77)	(0.67, 0.96)	7.05	5.73	83	-1.29 (1.29)	(-1.57, -1.01)
>250% (143, 52%)	2.83	3.47	141	0.63 (0.65)	(0.53, 0.74)	7.76	6.17	108	-1.63 (1.39)	(-1.89, -1.36)
Disease status										
Pre-cancer										
No (215, 78%)	2.66	3.44	213	0.77 (0.70)	(0.68, 0.87)	7.56	6.05	158	-1.51 (1.27)	(-1.71, -1.31)
Yes (14, 5%)	2.91	3.59	14	0.68 (0.65)	(0.31, 1.06)	8.57	6.50	7	-2.07 (1.24)	(-3.22, -0.93)
Cancer Type										
Other cancer (137, 50%)	2.54	3.37	137	0.83 (0.70)	(0.71, 0.95)	7.10	5.85	120	-1.27 (1.23)	(-1.49, -1.04)
Breast cancer (139, 50%)	2.86	3.50	136	0.64 (0.70)	(0.52, 0.76)	7.70	6.03	88	-1.64 (1.52)	(-1.96, -1.32)
Intervention status										
Location										
Ukiah (177, 64%)	2.52	3.42	176	0.90 (0.68)	(0.80, 1.00)	8.06	6.36	139	-1.70 (1.23)	(-1.90, -1.49)
Mendocino (99, 36%)	3.03	3.45	97	0.43 (0.66)	(0.29, 0.56)	5.91	5.04	69	-0.88 (1.48)	(-1.23, -0.52)
Telephone delivery										
No (124, 45%)	2.78	3.44	124	0.66 (0.69)	(0.53, 0.78)	7.31	5.84	98	-1.49 (1.29)	(-1.75, -1.23)
Yes (99, 34%)	2.69	3.43	94	0.74 (0.73)	(0.59, 0.89)	7.06	5.88	62	-1.16 (1.14)	(-1.45, -0.87)
Interventionist survivor										
No (134, 49%)	2.99	3.43	132	0.43 (0.67)	(0.32, 0.55)	6.27	5.28	89	-0.99 (1.45)	(-1.30, -0.69)
Yes (141, 51%)	2.42	3.44	140	1.01 (0.62)	(0.91, 1.12)	8.19	6.45	118	-1.74 (1.22)	(-1.96, -1.51)

Figure 6. Summary of significant predictor variable performance in multivariable linear regression.

Variable	Change in Decision Self-Efficacy						Change in Anxiety				
	Coef	P-value	Lower Bound	Upper Bound	Std Coeff		Coef	P-value	Lower Bound	Upper Bound	Std Coeff
Baseline anxiety (0 to 10)	-0.026	0.040	-0.051	-0.001	-0.104		-0.216	<0.001	-0.282	-0.149	-0.423
Location of first intervention (0=Ukiah, 1= Mendocino)	-0.201	0.018	-0.366	-0.035	-0.139						
Baseline decision self-efficacy (0 to 4)	-0.655	<0.001	-0.733	-0.618	-0.762						
Interventionist volume since 2003	0.001	0.038	0.000	0.002	0.123						

Question 3: Were There Any Significant Predictors of Variation in Decision Self-Efficacy and Anxiety?

Compared to our simple linear regression, considering predictor variables together simultaneously meant that we dropped five variables that previously were significant predictors of change in decision self-efficacy: income; cancer stage; cancer type; and whether the interventionist was a cancer survivor. The final model therefore included baseline anxiety (a continuous variable on a scale of 0-10 with responses ranging from 1-10) and baseline decision self-efficacy (scale and range of 0 to 4); location (coastal versus inland offices of the resource center) and interventionist volume . Among the 12 interventionists, volume of experience administering question-listing sessions ranged from 1 to 89.

Location was correlated with interventionist volume (correlation coefficient r=-0.62) and also with whether the interventionist was a cancer survivor (r=-0.77). We therefore considered alternative multivariable models, including one substituting location for cancer survivor, but our final model explained the largest proportion of the variance (65%) so we adopted it as the best fit.

Considering predictor variables together simultaneously also led us to drop five variables that previously were significant predictors of change in anxiety: baseline decision self-efficacy; location; telephone delivery; interventionist cancer survivor;

and volume. The final model included only baseline anxiety. See Figure 6 for details.

Discussion and Conclusions

For each of the study questions, we now interpret the findings, with special attention to surprising or otherwise interesting results, and in comparison with prior publications in the literature.

Question 1: Was the Question-Listing Intervention Associated With Changes in Decisional Self-Efficacy and Anxiety?

Each outcome saw a marked shift, reflecting improvement, in the distribution from baseline to post-intervention. These results are consistent with other studies that have found improvements in decision self-efficacy. The same intervention was associated with improved decision self-efficacy in this community setting among breast cancer patients,[17] among breast cancer patients in a US academic setting,[13] among blood cancer patients in a US community setting,[18] and among prostate cancer patients in Scotland.[19] Related interventions, such as decision aids for hormone replacement therapy,[37,38] colorectal cancer[39] and prostate cancer,[40] have also been associated with improvements in decision self-efficacy. Our results therefore extend to a rural population for the first-time results that have been found in urban settings.

We were interested to find reductions in anxiety, as there have been mixed results reported in the literature. In a study of our intervention with blood cancer patients in the US [18], we saw a reduction in the same measure of anxiety from a mean of 4.6 pre-intervention to 3.5 post-intervention, a similar relative reduction (24%) as we saw in this study (7.26 to 5.87 or 19%), but at lower absolute levels of anxiety. Anxiety remained higher after our intervention than it was before the intervention in the prior study. One possible explanation for this is that patients who received our question listing intervention were usually preparing for a visit that was occurring very soon after their diagnosis, having been referred in many cases to the resource center by the diagnosing physician. Therefore, while our intervention was associated with significant reductions in their anxiety, patients were likely still very anxious because they had not yet discussed treatment options and outcomes with a specialist. In the prior study, patients had self-referred to a resource center that typically does not see patients immediately upon their diagnosis. These patients may have had more time to adjust to their cancer diagnosis. Based on this finding, we plan to measure referral source and time since diagnosis in future studies of our intervention. Another possibility is that patients diagnosed with cancer in this rural, medically underserved community may experience higher levels of anxiety than patients in the more urban setting of the prior study, due to a disparity in their access tomedical care.

Question 2: Did Changes in Decision Self-Efficacy and Anxiety Vary Across Subsets, Including Patients Who Did not Have Breast Cancer?

Given that almost all respondents reported paired improvements, it makes sense that all of the subsets with more than 7 patients reflected mean improvements in the outcomes. This finding suggests that the intervention is patient-centered enough to produce good effects across subsets of patients, including both genders, across ages and income levels, cancer types and stages, and various interventionists (including some who were cancer survivors and some who were not) delivering the intervention either in person or by telephone. There were relatively few non-white clients in the sample (28 or 10%). These clients had lower decision self-efficacy and higher anxiety at baseline than whites, but reported the same improvements as whites. This is consistent with our prior examination of Hispanic ethnicity patients reviewing decision aids in an academic medical setting [41]. There we found that Hispanic patients reported higher baseline decisional conflict than non-Hispanics, while reporting larger decreases, which represent improvements on that measure.

Question 3: Were There Any Significant Predictors of Variation in Decision Self-Efficacy and Anxiety?

Patients starting in different states reported different intervention effects, making the baseline scores significant predictors of the change scores. One explanation may be that patients reporting lower baseline anxiety and higher baseline decision self-efficacy gave themselves less leeway to report improvement, without yet knowing how they would feel after the intervention. Conversely, patients with higher baseline anxiety and lower baseline decision self-efficacy left themselves more room to

report improvement. As a result, patients with the same subjective response to the intervention could have reported different improvement levels, based on whether they were blocked from reporting the full perceived effect by a floor or ceiling when they reached the limit of the scale. Thus, the finding that the baseline scores were significant predictors of the change score could be spurious. Future researchers may want to consider adding retrospective pre/post assessments to disentangle the floor or ceiling effects from the perceived intervention effects.

Patient location referred to the fact that the resource center has two geographically distinct sites, one inland office in Ukiah, and one coastal office in Mendocino village. Residents on the coast reported higher baseline decision self-efficacy (mean 3.03 versus 2.52 for Ukiah) and lower baseline anxiety (mean 5.91 versus 8.06 for Ukiah). This played in to the floor and ceiling effects described above. In addition, location was highly correlated with interventionist volume and whether the interventionist was a cancer survivor. This collinearity means it was difficult to interpret our regression results, which remain exploratory and hypothesis-generating.

Limitations and Strengths

The strengths of this study include that it examined the effectiveness of an evidence-based intervention translated into a rural, underserved community setting and sustained there. Our intervention adds to the literature because, in contrast with self-administered prompt sheets, it is administered by a trained facilitator who helps patients verbally brainstorm a personalized list of questions expressed in their own words.

Our study represents practice-based evidence with high external validity, meaning the study conditions were representative of real-world conditions in the way the intervention was delivered, and the range of clients. One of the study outcomes, decision self-efficacy, is part of a conceptual model, the Ottawa Decision Support Framework, that relies on self-efficacy as a known predictor of behavior and health outcomes. We reported on responses to a survey instrument that has documented psychometric properties and that has been used in other studies with similar populations.

Our second study outcome, anxiety, was measured using a study-specific, single-item survey instrument. Other studies that compared single item anxiety measures similar to ours to a 20-item standardized scale found that the single item was an acceptable substitute [24,25]. However, longer instruments are generally more reliable measures of psychological constructs such as anxiety. In addition, we had a large number (86 out of 276) of missing responses to the anxiety questions due to errors in reproducing the anxiety question on resource center evaluation forms. We cannot know whether the non-respondents would have reported different results than what we found from respondents.

Both of our outcome measures were near-term patient-reported outcomes. We do not have direct evidence from this study of longer lasting effects. Leaders of the community agency implementing the intervention felt that these were the most appropriate outcomes for their program to track because they

could be closely linked, conceptually and chronologically, to the intervention. In addition, community representatives felt that improving decision self-efficacy and reducing anxiety are important components of patient-centered care, and that improving these outcomes would be worthwhile even if the intervention had no longer-term effects. This is consistent with the view of the Institute of Medicine that getting through treatments more psychologically supported is an important end in itself[42] because it improves the patient experience in health care. Nevertheless, future studies should examine downstream effects of question-listing, including whether it changes treatment decisions, adherence to those decisions, clinical outcomes, overall resource use, and quality of life.

Other weaknesses of this study include that it consisted of a pre/post design without a control group. The main threat to internal validity for this design is that the respondents might have reported similar improvements through the simple passage of time. This maturation bias may have been mitigated by the fact that program staff administered the survey instruments immediately before and immediately after the intervention. However, the fact that the same people administered the intervention and the surveys creates a potential motivational or social agreement bias, as respondents might feel socially beholden to the interventionists and respond with a desire to please them.

Our data set included responses to survey items that asked patients to rate, quantitatively, their decision self-efficacy and anxiety. Thus, we lacked qualitative data that might have added more insight to our findings.

Some of our analytic results may have been distorted by collinearity. For example, two long-time (and therefore high volume) program staff who are breast cancer survivors work at the inland (Ukiah) office, whereas more recent (and therefore lower volume) program staff who are not cancer survivors work in the coast office (Mendocino Village). Thus, the location is strongly associated with volume of experience and survivorship status, and all are associated with the change in decision self-efficacy. This kind of collinearity can distort the results of a linear regression, which is predicated on linearly independent variables.

We believe that these issues do not threaten the overall findings, which show robust intervention effects across subsets. However, they reinforce the fact that our regression results should be interpreted as exploratory and hypothesis generating. In addition, we do not know what particular features of the intervention, if any, may have contributed most to the effects on decision self-efficacy and anxiety.

Current Translational Status and Future Directions

The question-listing intervention is now being implemented and sustained as part of routine care in several academic and community settings. It was first implemented at UCSF and has been sustained there by internal and external funds since 1998 as part of patient-centered care initiatives. The resource center featured in this study also has sustained the delivery of question-listing services by paid staff since 1998. The resource center provides all of its services free of charge through philanthropic grants and donations from foundations, corporations, and individuals. Since 2012, another non-profit agency, the Cancer Support Community, has also sustained with philanthropic support its implementation of our question-listing intervention. It delivers the intervention across the USA through a nationwide toll-free telephone line, in English and Spanish, free of charge to people with cancer, as well as in-person at physical locations in 33 communities [43]. Since 2013, the Center for Shared Decision Making at Dartmouth-Hitchcock Medical Center has also sustained its implementation of question-listing with philanthropic as well as internal budgetary support [44].

These organizations share a common motivation to implement a visit preparation intervention that addresses patient needs for short-term assistance with navigating treatment decision-making consultations. Helping patients ask questions is, in their view, an ethical imperative to advance the patient-centered outcomes of informed consent and informed choice.

These agencies demonstrate the viability of implementing such a question-listing service in the voluntary sector with philanthropic support. This leaves open the question as to whether other payers, such as private or government health care plans, will fund this or similar question-listing or other visit preparation services. Such payers are increasingly looking for interventions that improve patient experience, improve outcomes, and increase health care economic value. As revealed in multiple studies cited above, question-listing does improve the patient experience of care. It remains to be seen whether question-listing contributes to different patient choices, resource use, or long-term outcomes. We also foresee the need to better understand what questions patients ask through content analysis, and what features of the intervention are most responsible for its effectiveness.

Our view is that question-listing merits wider adoption because it improves the patient experience of care. Our research agenda now turns to mechanisms for reducing the cost of delivering the intervention, to reduce barriers to adoption. We are exploring the feasibility of delivering our question-listing intervention on a large scale using trainees who will earn academic credit and gain practical experience while serving patients at low cost [15,45].

Acknowledgments

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This study received ethics approval from the UCSF Committee on Human Research. For this type of study fo

Conflicts of Interest

The authors have declared that no competing interests exist.

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Evidence, Research

Information and Communication Technologies to Support Chronic Disease Self-Management: Preconditions for Enhancing the Partnership in Person-Centered Care

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Abstract

Objective: In order to alleviate the pressure on health care systems exerted by the growing prevalence of chronic diseases, information and communication technologies (ICT) are being introduced to enable self-management of chronic diseases by supporting partnerships between patients and health care professionals. This move towards chronic disease self-management is accompanied by a shift in focus on integrating the patient with his or her perceptions on the chronic disease as a full-fledged partner into the health care system. This new perspective has been described as "person-centered care" (PCC). To date, information and communication technologies only partially build on the principles of PCC. This paper examines the preconditions of ICT to enable a person-centered approach to chronic disease management.

Methods: Using cancer treatment as a case study for ICT-enabled PCC, we conducted a comparative analysis of thirteen scientific studies on interventions presented as ICT-enabled PCC for cancer treatment, to answer the research question: What are the preconditions of ICT-enabled PCC in chronic disease management? Based on the intended and actual outcomes, we distilled in several analytic steps the preconditions of ICT-enabled PCC for chronic disease self-management.

Results: We distinguished four user-related preconditions of ICT-enabled PCC: (shared) decision making, personalized ICT, health-related quality of life, and efficiency.

Conclusions: We argue that these four preconditions together can improve people's self-management of chronic diseases by strengthening the partnership between the patient and the healthcare professional. Moreover, the study revealed a discrepancy between intended and reported actual outcomes in terms of realizing person-centered care.

Introduction

Chronic noncommunicable diseases are the leading cause of illness, disability, and mortality, exerting significant pressure on the sustainability of worldwide health care systems [1]. Management of a chronic disease is often a lifetime task for which the patient is responsible on a day-to-day basis. This requires on the one hand "self-management" by the patient, involving active participation of people in their own health care process, and on the other requires helping them and their families to accrue the knowledge, confidence and skills to manage their condition [2].

Successful self-management of a chronic disease allows people to handle their life with some degree of independence despite their medical condition, and to feel healthy despite their limitations [3]. A key characteristic of self-management is a collaborative approach to the care of chronic illness, in which patients and professionals form a partnership focused on the

patient [4]. Thus, rather than perceiving health care professionals as experts and patients as subjects that bring little to the table besides their illness, a self-management partnership means that people with chronic conditions become their own principal caregivers, and health care professionals are seen as "consultants" supporting them in this role [2].

Information and Communication Technologies (ICT) are considered an important enabler of such partnerships, as ICT can offer ways to connect chronic patients and their health care providers around the clock and at a distance, contributing, for example, to more self-monitoring and shorter hospital stays [5,6]. Nonetheless, the partnership is often neglected in the design of ICT applications aimed at supporting chronic disease self-management [7,8]. ICT applications for health care purposes are regularly developed for rather than with the intended users [9]. Moreover, ICT applications typically do not take into account the partnership between patients and health care professionals [10], and are focused on only one of these parties

rather than considering both [11]. This lack of consideration for both the patient and the health care professional, as well as their partnership, increases the risk that ICT applications are mismatched with user needs, and that the technology ends up lacking meaning in practice for both patients and health care professionals [12]. Thus, while more and more health care-supporting interventions and applications are being designed, it remains unclear whether and how such interventions in fact contribute to better self-management of chronic conditions. This is problematic, because when the promise of ICT-enabled support tools is not realized, not only significant investments in ICT solutions are wasted, but most of all: collaborative partnerships between patients and health care professionals within health and health care are not optimized.

In this paper, we aim to generate understanding of the preconditions toward realizing ICT-enabled approaches to support chronic disease self-management. We opted for the term preconditions as these best describe the necessary but not exclusive characteristics to realizing actual use. Identifying preconditions to ICT-enabled chronic disease self-management is an important step in improving the technology design process toward better support of the partnership between the patient and health care professional. Building on our analysis, we explain how ICT can be better tailored toward self-management of chronic diseases, for both patients and health care professionals. We draw on the concept of person-centered care (PCC) to guide this analysis, whereby a patient's personal context and situation informs and guides the design and implementation of their health care. Our case study, based on an analysis of thirteen studies in which ICT was presented as an important means to support person-centered chronic disease management of cancer, is therefore guided by the research question: What are the preconditions of ICT-enabled PCC in chronic disease management?

We identified four preconditions for ICT-enabled person-centered care, but found that while these preconditions are sometimes met, the intended outcomes of ICT-enabled person-centered care are not always realized. We explain this discrepancy by drawing on an affordances perspective, which forefronts the actual use, and not only the designed intent of technology. We first introduce the theory on person-centered care that informed our study.

Person-Centered Care

Person-centered care (PCC) is a systematic approach to disease management that involves the patient as an equal partner in the care process [13]. Initial studies on person-centered care suggest that a fully implemented PCC approach keeps people more resilient, shortens hospital stays and improves quality of care [14,15]. PCC involves three core components: initiating the partnership, by eliciting a detailed patient narrative; working the partnership between patient and health care professional, by implementing the narratives in the care process through shared decision making; and safeguarding the partnership, by documenting the partnership in the patient record [13]. The patient narrative is the person's personal account of his illness and symptoms, and their impact on his life. It captures the

person's suffering in an everyday context, in contrast to medical narratives that reflect the process of diagnosing and treating the disease [13]. The PCC components build on each other, and can be reiterated.

PCC can be considered a specific type of shared-decision making, which involves an interaction process established in the partnership between patient and health care professionals [7,15]. Through the combination of this process orientation with a narrative orientation, PCC emphasizes the need to build partnerships based on the personal, individual meaning that a (chronic) disease has in a person's life. As this is a highly personalized process, ICT applications have the potential through their flexibility to be particularly suitable for supporting these partnerships [6]. Yet, the development of such ICT support for PCC is still in its infancy [7,8]. Our study seeks to further develop this understanding by way of a case study that we now introduce.

Methods

Setting and Sample

Our dataset consisted of thirteen cases (listed in Multimedia Appendix 1) derived from a prior large scoping review of literature on ICT interventions in a wide variety of self-management and connected-care activities [8], which presented ICT-enabled health care as an important means to support person-centered chronic disease management. The studies we selected for our analysis followed what could be considered as ICT-enabled person-centered care for chronic conditions, meaning the ICT-interventions were aimed at meeting the three established components of person-centered care: Initiating the partnership (patient narratives); working the partnership (shared decision making) and safeguarding the partnership (documenting the narrative) [13]. We focus on a single chronic condition cancer care as a means for comparison across studies. By focusing on one chronic condition we were better able to compare across studies. Cancer is one of the main types of non-communicable chronic diseases and the condition is a leading cause of disease worldwide. The sample of cancer yielded the largest category within the scoping review of the "big five" chronic conditions (diabetes mellitus, cardiovascular disease, chronic respiratory disease, cancer, and stroke) studied. Moreover, ICT interventions to support cancer care cover a wide variety of self-management and connected-care activities and are, in that sense, a good example of ICT-enabled PCC toward chronic disease management [16,17].

Study Design

We analyzed thirteen cases of cancer care by following the initial steps for structuring qualitative data in new concept and theory development, as described by Gioia [18]. The Gioia methodology is a systematic approach using interpretative coding, which was useful for our aim of distilling the preconditions of ICT-enabled PCC based on evidence derived from the selected cases. First, initial (open) coding was conducted in each of the thirteen studies, using NVivo software, whereby we particularly sought to identify how ICT usage was described as a support of chronic disease management in a person-centered approach to care. Second, the first author's

coding was reviewed by the other authors, after which the group of authors grouped them according to similarities and differences in ICT-enabled person-centered care. We created categories by seeking similarities among the codes, grouping these under so-called first-order concepts (summarized in Figure 1), and discussing and adapting these to ensure these first-order concepts were appropriately captured. We looked for patterns among the core concepts, distilling how the described ICT interventions

supported disease self-management of cancer in a person-centered approach to care. Third, we identified theoretically-supported second-order themes ("preconditions") that emerged from the first-order concepts. In the preconditions we articulated the outcomes of the first-order concepts in the interventions studied that afforded a person-centered approach to care, enabled by ICT. The resulting data structure is shown in Figure 1.

Figure 1. Data structure of ICT enabling PCC.
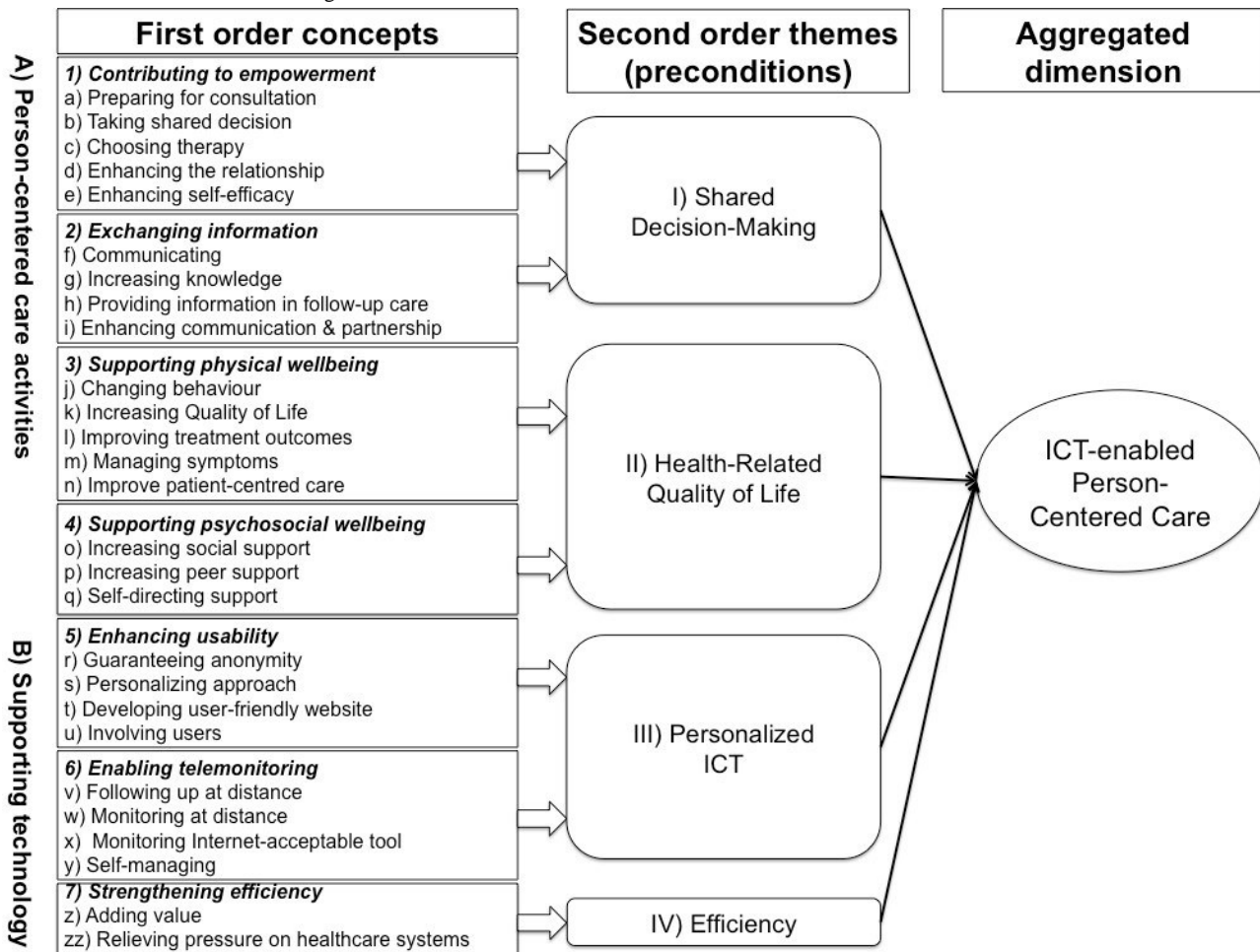
We based our preconditions on the ICT-interventions mentioned in the studies. However, not all intended outcomes described were realized. To distinguish intended versus actual outcomes in terms of PCC, we reverted to the originally selected text segments in the cases we studied (summarized in Table 1). These categories were used to recognize if the ICT-interventions enabled person-centered care in chronic disease management not only in theory, but also in health care practice.

Results

We derived seven so-called "first-order concepts" related to ICT-enabled PCC: contributing to empowerment; exchanging information; supporting physical wellbeing; supporting psychosocial wellbeing; enhancing usability; enabling telemonitoring; and strengthening efficiency (Figure 1). These first order concepts can be seen to represent on the one hand person-centered-care-related activities (A) and on the other the supporting technology (B).

Regarding the person-centered care activities (A), we first identified activities contributing to empowerment (1) that engage patients to "make active choices in their recovery" such as electronic support groups for breast carcinoma [19] These activities were manifested in the form of: preparing for the consultation (1a), taking shared decisions (1b), choosing therapy (1c), enhancing the relationship between the patient and the health care professional (1d) or enhancing self-efficacy (1e). For instance, patient empowerment was mentioned in four studies as being the result of "info-decisional empowerment" (information provision to support decision making), sharing information, and interactive health communication [20,23].

The second first order concept we identified was exchanging information (2), which involves staying in touch outside of regular scheduled sessions, not only with health care professionals but also with supporting peers [19] Exchanging information was manifested through communicating (2f), increasing knowledge (2g), providing information in followup

care (2h) and enhancing communication and partnership (2i). Articles describing these activities suggested that ICT increased the opportunities for accessing and exchanging information (eg, [23,17]), as described in the study on the development of a useful, user-friendly website for cancer patient followup by Bartlett and colleagues [17]: "Use of the internet for information exchange between patients and health care staff may provide us a useful adjunct or alternative to traditional followup."

Supporting physical wellbeing (3) is the third first order concept we distinguished, and involves striving to be as healthy as possible despite the disease [3]. This was manifested in the form of changing behavior (3j), increasing quality of life (3k), improving treatment outcomes (3l), managing symptoms (3m) and improving patient-centered care (3n). For instance, physical well-being, either through behavior change or management of symptoms or treatment, was one of the desired outcomes either through a telephone-based physical activity intervention [24], an online support group for prostate cancer survivors [25], an eHealth application for personalized illness management support [26], a telemedicine system supporting head and neck cancer patients,c and symptom telemonitoring in advanced lung cancer [27]. All cases aimed to have an impact on health-related quality of life. For example, telemedicine systems supporting head and neck cancer patients during the postoperative period at home were beneficial for the quality of life of this group of cancer patients and added to the physical wellbeing of the patients [16].

Next, supporting psychosocial wellbeing (4) involves increasing psychosocial support from being connected to others, for example through a novel patient community. For instance, patients who used an Internet-based, interactive, integrated support system for cancer patients experienced greater social support during the intervention period [28]. Social media also played an important role in psychosocial wellbeing, in particular the use of Twitter as described by Sugawara et al [23]. due to its ability to promote direct interaction between cancer patients.

We also found references to the supporting technology (B), and how it supported cancer self-management in a person-centered manner. First, we identified technology related to enhancing usability (5), which involves the ease of use or the learnability of the ICT applications. One of the few studies that suggested user-involvement in the development process as a means to strengthen usability was Bartlett and colleagues' [17] analysis, whereby the authors suggest that: "Involving users at developmental stages of eHealth systems is generally considered good practice and can ensure the application under development is both user-friendly and perceived as useful." Within the cases, usability was represented by guaranteeing anonymity desired by the patients (5r), personalizing approach (5s), developing user-friendly website (5t) and involving users (5u). For example, one of the studies focused on the usability, feasibility and acceptability of a user-friendly and useful website with the potential for use in a "training and website" followup model in cancer care [17].

Enabling telemonitoring (6) in a person-centered approach to care included combining various information technologies for remotely monitoring patients [16,28,29], providing the possibility to following -up at distance (6v), monitoring at

distance (6w), monitoring if Internet is an acceptable tool (6x) and self-managing (6y).

Finally, strengthening efficiency (7) involves a substitute for traditional face-to-face followup, which might not be the most (cost-) efficient use of physician and patient time. ICT can offer ways to connect chronic patients and their health care providers around the clock and at a distance. For both the patient and the health care providers the substitute of ICT should be efficient and adding value (7z). Efficiency was sometimes mentioned under the umbrella term "relieving the pressure on health care systems" (7zz). Here, ICT was used for followup at a distance replacing followup visits. This is efficient for both patient and health care professional but is also a means to reduce the pressure on the health care system, including the health care professionals [17].

Preconditions of ICT Enabling Person-Centered Care

In our third analytical step we developed so-called second order themes based on an iterative analysis between our empirical findings and the literature on person-centered care. We identified four second order themes or "preconditions" of ICT as enabling person-centered care: shared decision making; health-related quality of life; personalized ICT; and efficiency (as summarized in Figure 1).

First, our analysis revealed that shared decision making was a prominent aim in ICT-enabled person-centered care. Shared decision making entails developing the health professionals' skills in involving patients in decisions related to their treatment, with the aim of increasing the patient's role in implementing this treatment, and ultimately improving decision quality [30]. ICT supported shared decision making by enabling patients to access online information and thereby gain additional knowledge and a better understanding of their illness, ultimately supporting shared treatment decisions. For instance, Izquierdo et al [31] show how a breast cancer Patient Decision Aid (PDA) allowed patients to adopt a more active role in the choice of treatment options in accordance with their medical and personal preferences.

Second, health-related quality of life consists of both physical and psychosocial wellbeing, which were important first-order concepts in the studies we analyzed. For example, health-related quality of life was mentioned as an outcome of the use of ICT, realized for example through telemedicine, in supporting patients during followup, and resulting in the perceived improvement of symptom control [16]. This was also realized through the use of social media and websites to enable peer support, resulting in an increase in psychosocial wellbeing [23]. The aim of an online self-help support for breast cancer patients was: "We hypothesized that breast cancer bulletin boards would prove to be effective in improving participant's quality of life as measured by a decrease in depression, and increase in psychosocial well-being and an increase in personal growth." [18]

We identified personalized ICT as a technology-oriented precondition of ICT-enabled PCC. This was manifested, for instance, through distance monitoring and followup in support of chronic disease self-management, where the capacity for

personalized ICT-interventions was recognized as a means to accommodate different needs among patients [17] indicate: "Differences were found between breast and prostate cancer patients and between patients with a first time diagnosis and metastases or recurrences. The large variations among patients in their use of WebChoice components demonstrate that patients' needs for support vary." [32]. We also found that peer-to-peer contact was particularly salient as a form of personalized ICT, in that online health communities afforded social support according to personal needs and preferences [20].

Finally, the precondition efficiency arises from the assessment of how ICT could be efficient for both the patient and the health care professional (7z) or to relieve pressure on the health care system (7zz). However, some studies demonstrated concerns that aiming for efficiency through ICT might replace human contact, rather than supporting regular health care efforts. That is, a one-sided emphasis on efficiency through ICT can weaken the partnership between patient and health care professional. For instance, the intended outcome of the ICT intervention of one of the studies was to develop a useful, user-friendly website for cancer patient followup and the site was tested on usability, feasibility and acceptability [17]. Its aim was to use the Internet for followup at a distance between patients and health care staff as a useful adjunct or alternative to traditional face-to-face contact for persons with a low risk of recurrence and with a low level of need. However, the study was initiated to address the burden imposed on health care systems by the growing amounts of followup visits, which put pressure on the workforce of health care professionals. Remote monitoring was proposed as a way

to diminish this pressure and decrease the costs, and considered as a low-cost solution to encourage patient self-management. It turned out that patients indicated they wanted to have a way of contacting their health care team without "causing hassle". However, this was "out with the scope of this study" [17]. Even though the patients were heard through focus groups and interviews, the intervention did not offer the services they wished for with their clinical team. Despite the fact that the authors of the study stated that user involvement in website design can ensure that patients' needs are met, the expressed wish of the patients for a "personalized" website was not realized. Thus, the intended use of personalized ICT was not the actual outcome.

Person-Centered Care: Technology in Use

As a final analytical step we sought to understand whether the preconditions we identified actually afforded ICT-enabled person centered care in the studies we analyzed. We compared the described intended use to the reported actual outcomes ("affordances") of the studies on ICT interventions in practice.

We identified three categories describing whether these routines were actually realized. The first category contained studies that did not report the actual outcome, for example when this was not part of the study design. The second category contained studies whereby the reported actual outcome was equal to the described intended use. The third category comprised studies whereby the reported actual outcome differed from the intended use. The described intended use and the reported actual outcomes are summarized in Table 1.

Table 1. Described intended use versus reported actual outcome.

Study	Described intended use	Reported actual outcomes
Care related		
Barlett et al (2012)	Provide information for follow-up care	No actual outcomes reported (only intended use)
	Follow-up at distance	
	Replace face-to-face contact	
	Self-management	
Gustafson et al (2008)	Regain competence	Enabled social support
	Increase health competence	Increased interactive support
	Empower decision-making	Increased quality of life
	Speed recovery	Increased health competence
	Enable social presence	Enabled feelings of relatedness
Izquierdo et al (2011)	Increase patient knowledge	Increased shared decision-making
	Promote shared decision-making	Achieved realistic expectations of disease
	Support therapy choice	Reduced passivity decision-making
	Empower decision-making	Increased knowledge on illness
Lieberman et al (2003)	Encourage empowerment patients	Reduced depression
	Reduce loss of hope	Reduced reaction to pain
	Reduce loss of control	Increased social support
	Reduce unwanted loneliness	Enabled anonymity
		Increased contact outside scheduled hours
Lieberman et al (2005)	Support peers	Increased psycho-social quality of life
	Support self-direction	
	Social support	
Ligibel et al (2012)	Increase physical activity	Changed behavior
		Increased physical activity
		Reached lifestyle intervention
Osei et al (2013)	Increase health-related quality of life	No actual outcomes reported (only intended use)
	Support family members	
Ruland et al (2010)	Prepare for consultation	Managed symptoms
	Document patient care	
Ruland et al (2013)	Manage symptoms	Reduced symptom distress
	Support clinicians in more patient-centered, illness-oriented consultation	Improved patient-centered care
	Tailor individual patient needs	Supported symptom management
	Manage disease	
	Manage symptoms	
Seckin et al (2012)	Empower patient	Prepared for consult
	Self-manage care	Supported coping with cancer
		Empowered info-decision support
Sugawara et al (2012)	Exchange information	Enabled anonymity
		Empowered through tweeting information
		Supported peers (using Twitter)
		Supported psychologically

Study	Described intended use	Reported actual outcomes
		Connected users
van den Brink et al (2007)	Improve quality of life	Increased impact quality of life
	Communicate	Decreased physical complaints
	Support peers	Reduced uncertainty and fear
	Retrieve information	Increased self-efficacy
		Improved symptom control
Yount et al (2013)	Relieve symptom distress	Failed to demonstrate efficacy
Technology related		
Barlett et al (2012)	Cost-efficient	Wanted to maintain face-to-face contact patient-health care professional (but not reached)
	Release burden on health care system	Trained prescription
	Monitor telehealth	Involved users in development of eHealth interventions (partly reached)
	Develop user-friendly website	Patients wanted "personalized" website with links to the clinical team (not reached)
		Accessed Internet had to do with personal choice and attitude than ability due to costs
		Differentiated factor of age
Gustafson et al (2008)	Integrate system of services	Integrated system of services more helpful than usual care
Izquierdo et al (2011)	Facilitate patient/physician decision-making	Increased understanding of disease
		Deepened awareness of other patients' experiences
		Encouraged shared decision-making
		Improved quality of decisions
Lieberman et al (2003)	Deliver electronic support groups through Internet	Occurred technological problems
		Worried clinicians that facilitation would be difficult because of lack usual cues
Lieberman et al (2005)	Validate Internet bulletin boards	Validated first step bulletin boards
Ligibel et al (2012)	Intervene with telephone-based exercise	Changed behavior test possible
Ruland et al (2010)	Tailor individuals through computerized assessment	Improved patient-centered care and patient outcomes, including reduced symptom distress and reduced need for symptom management support
Ruland et al (2013)	Support cancer patients in illness management	Effectively supported by computer tool
Seckin et al (2012)	Empower patients	Cyber supported patients for knowledge about their illness and treatment
	Manage computer technology-based information on diseases	
Sugawara et al (2012)	Role Twitter in the life cancer patients	Exchanged information via Twitter
van den Brink et al (2007)	Tele monitor to bridge gap after discharge	Felt secure
Yount et al (2013)	Monitor symptoms	Efficiency not shown

A second category contained studies where the reported actual outcome was equal to the intended use described. An example of this category is the study by Van den Brink and colleagues [16], which focuses on the impact on quality of life of a telemedicine system in support of cancer patients. In this case, the partnership was supported. The intervention group was provided with a laptop and access to a telemedicine support system during the first six weeks after discharge. The system offered possibilities for communication, access to information, peer support and monitoring at home. The study reported that the telemedicine system proved to be beneficial for the quality of life of cancer patients [16].

A third category, which we encountered most often, comprised studies where the reported actual outcome differed from the intended use. These studies revealed a discrepancy between

what was described as the intended use of ICT to support chronic disease management and how ICT was actually used in practice, in terms of realizing person-centered care. For instance, in a case describing the development of a useful, user-friendly website for cancer patient followup, the study disclosed that the explicit wish of the patients was to have a way of contacting their health care team without "causing hassle." [17] However, in the actual realized outcome, the focus was primarily on relieving the burden imposed on health care professionals and the health care system in general through the growing amounts of followup visits. Thus, while remote monitoring of persons with a low risk of recurrence and a low level of need was proposed as a low-cost way to diminish this pressure, decrease costs, and support patient self-management, the intervention ultimately did not offer the services and interactions with their clinical team the patients wished for, even though the patients were consulted in the design process. The intended outcome more patient involvement and patient self care was not realized because patients' wishes were not met in the design and development process of the ICT-intervention.

Across these categories, only a few studies showed a clear focus on the partnership involving both patients and health care professionals. Nonetheless, partnership is a prerequisite following the original definition of person-centered care by Ekman and colleagues, stating that person-centered care is a systematic approach to disease management that involves the patient as an equal partner in the care process [33] An example where this prerequisite was met was the development process of a patient decision aid (PDA), in which both breast cancer patient and health care professional were involved. "The PDA for breast cancer…has succeeded in improving the quality of decisions for specific situations and has encouraged a shared decision making approach in which both patients and health care professionals take on a participative role." [31] Clearly, inclusion of the partnership remains a challenge that has, yet, to be overcome if the promise of ICT-enabled PCC is to be met.

Discussion

The resources needed to support chronic diseases are putting increasing pressure on health care systems. To alleviate this pressure, information and communication technologies (ICT) are being introduced to support self-management of chronic diseases. This move towards chronic disease self-management involves integrating the patient as a full-fledged partner, also described as "person-centered care" (PCC). We argued that ICT only partially builds on the principles of PCC [8], and that explicit understanding of the mechanisms supporting the partnership between patients and health care professionals in ICT-enabled person-centered care is lacking. We therefore sought to identify ICT preconditions in support of chronic disease management as a means to better facilitate a person-centered approach to care and the partnership between the patient and the health care professional in particular.

By analyzing studies reporting a person-centered approach to ICT-enabled cancer care we identified four preconditions: shared decision making, personalized ICT, health-related quality of life, and efficiency. Each of the preconditions involves

participation of both patient and health care professional, and emphasizes their collaboration in a partnership rather than treating each partner as an isolated entity. Several studies show that the partnership between patient and health care professional is changing [2,4,15,32]. In participatory medicine, for example, patients are encouraged to act as full partners and are valued as such [32]. ICT has the potential to support participatory medicine by equipping, enabling, empowering and engaging patients, thereby creating a more equal partnership between patients and the health professionals and systems that support them [34].

Through our focus on the health care partnership we extend prior studies addressing the use of ICT to support self-management of chronic diseases that attend to either the experiences of the patients or the health care professionals, but not the participation of both [7,8]. Indeed, we argue that upfront inclusion of different stakeholders of care [35,36] is critical toward more successfully developing and eventually integrating ICT interventions in the health sector. Based on these arguments, we propose the preconditions for a person-centered approach to ICT-enabled care to enhance the effectiveness of the care partnership.

In addition to the four preconditions, we found that the intended use of ICT interventions to enable person-centered care often diverged from the actual use. By analyzing both the intended as well as reported actual outcomes, we sought to understand not only what technology was designed for, but also what it engendered in health care practices. To explain this discrepancy, a "technology affordances" lens is appropriate. Technology affordances relate to the possibilities and opportunities that arise from users engaging with the technology, and take into account the resulting potential behavior changes [33]. In other words, sometimes users tend to use ICT applications differently than intended [37,38] which makes it crucial to examine how users actually engage with a technology over time within a particular setting, and how ICT applications are embedded in their daily practices.

A second insight that the affordances perspective has to offer is that people need to engage with ICT applications to make them have impact. The extensive integration of ICT ushers in significant changes to the actual "fabric" of professional engagement [39]. Our analysis confirmed that simply replacing parts of the workflow with ICT-enabled ways of working barely affects practices [36,40], and ICT cannot be simply added on as an afterthought.

The majority of the cases that we studied (Table 1) showed a discrepancy between the intended use and the reported actual outcomes. Either, the reported outcomes differed from the intended use or the outcomes were not reported at all. Our findings suggest that such a mismatch between intended use and reported actual outcomes might be prevented in future by meeting the preconditions for ICT-enabled PCC.

Limitations and Further Research

For this study we relied on secondary data of a large scoping review that were not collected for the aim of this study, so we may have missed relevant preconditions that were not described

in the studies used. However, we only selected studies that were explicitly aimed at describing the outcomes of ICT-enabled PCC interventions. This means that the likelihood of important omissions is small. Nonetheless, case studies aimed at analyzing ICT-enabled PCC in practice would be useful to validate our findings. This would also enable more in-depth analysis of the ways in which the technology is being embedded within the partnership and the wider organization in which the patient and the health care professional participate.

Another limitation of the study is that it comprises a sample of ICT-enabled cancer treatment cases, excluding other chronic diseases. By limiting ourselves to cancer, we may have missed activities that are specific to other chronic diseases. Further research comparing different chronic disease is a useful way to overcome this limitation and extend the validity of our findings.

This study reflects data from thirteen studies. Since not all of them include a complete overview of the demographics, we lack detailed insights of the interactions between the technology used and the demographics of the persons using it. We therefore do not know to what extent certain outcomes are specific to certain groups, such as effects of education level, cultural background, or age on the engagement with ICT applications.

Overall, more knowledge is needed on the actual use of ICT-interventions in practice and how this supports the partnership between patients and health care professionals in particular. Drawing on the basis we provide in this study, a next step is to combine health innovation research with research on the design of technology-enabled health applications (or "eHealth" [32,34,35]) in a person-centered approach, taking into account the context in which technology is being applied, and most importantly, how people using these technologies experience them in relation to their disease self-management.

Conclusion

The primary aim of this study was to determine the preconditions of ICT-enabled person-centered care to support a self-management partnership between chronic disease patients and health care professionals. By examining ICT as an important means to facilitate a partnership between patients and health care professionals, we contribute to a nascent body of literature on ICT-enabled health care (or eHealth), and to the relatively new field of research that combines person-centered care and ICT [6,7].

We identified four preconditions to ICT-enabled PCC: shared decision making, personalized ICT, health-related quality of life, and efficiency; but also found that intended and actual use of interventions often diverged. The preconditions all involve participation of both patients and health care professionals as partners in the self-management process. This makes ICT-enabled PCC a partnership that can prove fruitful in furthering participatory medicine.

Multimedia Appendix 1
Selected articles on ICT-enabled person-centered care for chronic disease management of cancer.
[PDF File (Adobe PDF File), 54KB - jopm_v9i1e14_app1.pdf]

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Abbreviations

ICT: information and communication technologies
PCC: person-centered care
PDA: patient decision aid

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