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## How to Conduct Qualitative Research on the Patient's Experience

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## How to Conduct Qualitative Research on the Patient's Experience

### Abstract

From a perspective of patient-centered healthcare, exploring patients' (a) preconceptions, (b) treatment experiences, (c) quality of life, (d) satisfaction, (e) illness understandings, and (f) design are all critical components in improving primary health care and research. Utilizing qualitative approaches to discover patients' experiences can provide valuable information for practitioners and investigators alike. In this paper, the author describes how researchers can select from among five major qualitative designs (i.e., primary qualitative research, qualitative evaluation, collaborative inquiry, mixed method, and qualitative meta-study) and five preeminent qualitative methodologies (i.e., descriptive, phenomenology, grounded theory, ethnography, and narrative) to create studies to meet their patient-centered research needs.

### Keywords

Patient Experience, Qualitative Research, Research Design, Patient-Centered Healthcare

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## **How to Conduct Clinical Qualitative Research on the Patient's Experience**

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*From a perspective of patient-centered healthcare, exploring patients' (a) preconceptions, (b) treatment experiences, (c) quality of life, (d) satisfaction, (e) illness understandings, and (f) design are all critical components in improving primary health care and research. Utilizing qualitative approaches to discover patients' experiences can provide valuable information for practitioners and investigators alike. In this paper, the author describes how researchers can select from among five major qualitative designs (i.e., primary qualitative research, qualitative evaluation, collaborative inquiry, mixed method, and qualitative meta-study) and five preeminent qualitative methodologies (i.e., descriptive, phenomenology, grounded theory, ethnography, and narrative) to create studies to meet their patient-centered research needs. Key Words: Patient Experience, Qualitative Research, Research Design, Patient-Centered Healthcare*

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In patient-centered healthcare (Stewart, Brown, Weston, McWhinney, McWilliam, & Freeman, 2003) the goal of treatment is to produce the most effective outcomes based upon the integration of "the conventional understanding of disease with each patient's unique experience of illness" (Weston & Brown, 1995, p. 23). In this clinical approach researchers from biomedical and psychosocial traditions work in concert to provide healthcare professionals the knowledge they need to conduct their evidence-based practice and practice-based evidence orientations (Gabbay & Le May, 2011; Heneghan & Badenoch, 2006) to treating the patient as a whole person. In this pursuit of clinical knowledge, qualitative researchers have been prominent in their contributions, as noted by McWilliam (1995).

Parallels between the patient-centered method and qualitative inquiry invite the application of this type of research to investigating patient-centered care. The patient-centered method is a process of acquiring understanding of a fellow human being. Patient-centered care focuses on the patient's disease and illness and on the patient as a whole person. In humanistic inquiry, the researcher and the research participant together strive to capture the needs, motives, and expectations of the participant to construct the interpretation of the experience. (McWilliam, p. 204)

Besides taking note of this affinity of worldviews, the more effective qualitative researchers have also been pragmatic in embracing the maxim, "All research is local." In doing so, these investigators take great care in learning how clinicians learn and focus their qualitative research studies to produce results that can inform the practice of patient-centered healthcare. The results of this conceptualization have led to the evolution of

clinical qualitative research – an approach to inquiry in which researchers apply qualitative research design and methodology to explore clinical phenomena in a manner that is sensitive to producing knowledge that addresses healthcare providers critical questions (Crabtree & Miller, 1999). This stance means qualitative researchers need to employ their naturalistic investigative skills to discover the “multimethod typology” of clinical research styles, aims, objectives, and research questions that help to organize how research is conducted in the clinical world (Miller & Crabtree, 1999, pp. 3-8). When qualitative researchers apply this orientation to their qualitative inquiry knowledge and skills, the results can be in a form that is more readily understandable and potentially more useful to healthcare providers (Stewart, Brown, Weston, McWhinney, McWilliam, & Freeman, 2003).

In clinical qualitative research, investigators explore a variety of healthcare phenomena including doctor-patient communication, healthcare services, healthcare providers’ experiences of providing care, and those experiences of the patients seeking the care (Crabtree & Miller, 1999). In this essay, the focus will be on one of these areas, the patient’s experience of healthcare. In discussion this clinical phenomenon, the goals will be (a) to present an overview of the prominent ways clinical investigators conceptualize and operationalize the patient experience in their studies, (b) to suggest ways to apply five major qualitative designs and five major qualitative research methodologies to explore patient experiences, and (c) to offer how to conceptualize, design, conduct, and report clinical qualitative patient experience research studies.

### **Overview of Qualitative Patient Experience Research**

In healthcare, understanding patients’ experiences allows providers to (a) appraise the effectiveness of their interventions; (b) comprehend how patients can mediate and moderate these interventions; (c) learn how patients’ particular worldviews can shape their perspectives on themselves, their caregivers, and their lives; (d) appreciate how patients’ culture can help shape their experiences as well as how patients engage with healthcare organizational cultures; and (e) evaluate and enhance training and education programs (Bate & Robert, 2007; Elliott, 2008; Elliott & James, 1989). Researchers may use different terms to describe their participants – Patient, Client, User, Consumer, Partner, or Expert. Investigators may also understand these participants’ messages from a continuum of perspectives – “Complaining, Giving Information, Listening and Responding, Consulting and Advising, and Experience-Based Co-Designing” (Bate & Robert, p. 10). Despite these differences, when studying patient experience, researchers always have many choices to make as to how they can conceptualize and operationalize this experiential phenomenon. These perspectives include the following:

#### **1. Preconceptions**

**Defined:** From this perspective, researchers learn what patients know, anticipate, and assume about the services, treatments, or personnel they will encounter in the course of their healthcare, with their aftercare, or with their quality of life. Discovering patients’ expectations can help professionals design their informational materials, organize their

orientations, and sensitize themselves for their interactions with interactions (Bate & Robert, 2007).

**Example:** Barry, C. A., Bradley, C. P., Britten, N., Stevenson, F. A., & Barber, N. (2000). Group patients' unvoiced agendas in general practice consultations: Qualitative study. *BMJ: British Medical Journal*, 320(7244), 1246-1250.

## 2. Treatment Experiences

**Defined:** From the perspective of the participants, researchers learn what the results of the services rendered were (outcome), how these services were experienced (process), how process of treatments was seen as leading or not leading to outcomes (progress), and how patients and primary care professionals and staff interact (communication). These findings help professionals adjust treatment, identify new effective practices, and triangulate participant data with other information (Bate & Robert, 2007).

**Example:** Guarino, H., Deren, S., Mino, M., Kang, S.-Y., & Shedlin, M. G. (2010). Training drug treatment patients to conduct peer-based HIV outreach: An ethnographic perspective on peers' experiences. *Substance Use & Misuse*, 45, 414-436.

## 3. Quality of Life

**Defined:** With this orientation, researchers seek to learn what patients value about their day-to-day and long-term lives and what changes or developments they worry may restrict or impact their lives' qualities and what changes if any have occurred after or during treatments. Knowing this information can help professionals customize their communication with their patients and sensitize themselves to outcomes unanticipated (Fayers & Machin, 2007).

**Example:** Bell, K., Lee, J., & Ristovski-Slijepcevic, S. (2009). Perceptions of food and eating among Chinese patients with cancer: Findings of an ethnographic study. *Cancer Nursing*, 32(2), 118-126.

## 4. Satisfaction

**Defined:** In these investigations, researchers envision participants as customers or consumers and seek to learn how satisfied or dissatisfied they are with their healthcare experiences. A sub-set of this research involves how patients value the services they receive and how this information helps healthcare systems determine "Return On Investment" (ROI). Learning this information can help professionals evaluate their programs and services and produce improvements and enhancements (Welch, 2009).

**Example:** Hartwell, H. J., Edwards, J. S. A., & Symonds, C. (2006). Foodservice in hospital: Development of a theoretical model for patient experience and satisfaction using one hospital in the UK. National Health Service as a case study. *Journal of Foodservice*, 17, 226–238.

## 5. Illness Understandings

**Defined:** In these studies, researchers learn how participants understand the nature of their disease, illness or condition. The research can focus on certain aspects such as diagnosis, etiology, or prognosis; or a combination. Becoming aware of this information can help professionals evaluate and improve their communication with primary healthcare consumers (Kleinman, 1988).

**Example:** Mahoney, J. S. (2001). An ethnographic approach to understanding the illness experiences of patients with congestive heart failure and their family members. *Heart & Lung*, 30(6), 429-436.

## 6. Design

**Defined:** In these studies, investigators collaborate with participants to conceive, create, evaluate, improve, and enhance policies, programs, services, interventions, processes, and outcomes. To accomplish these goals researchers actively seek participants' perspectives and observe participants' utilization patterns and use this information throughout the design conceptualization, operationalization, and evaluation phases (Bate & Robert, 2007).

**Example:** Bate, P., & Robert, G. (2006). Experience-based design: From redesigning the system around the patient to co-designing services with the patient. *Quality and Safety in Health Care*, 15, 307–310.

## Application of Five Major Qualitative Designs to Patient Experience Research

Qualitative research is the rigorous attempt to produce findings or results by describing, explaining and/or interpreting qualitative patterns in terms of words, numbers, matrices, pictures, sounds, or other forms of representation. Qualitative research is well-suited for naturalistic inquiry, discovery-oriented studies, learning perspectives of others, and for studying complex and natural phenomena. In Clinical Qualitative Research, the basic strengths of the family of qualitative research designs and methodologies are used to explore questions of clinical importance. For example, clinicians are interested in knowing the effectiveness and efficacy of their treatments. They also want to know how they can improve treatment processes so outcome levels can be improved. In addition, clinicians are keen to learn more about their patients in order to understand how patients experience their medical conditions, their treatments, their treatment's outcomes, and the professionals who are providing their care. By adapting basic qualitative research designs and methodologies to help clinicians address these areas of curiosity and concern, clinical qualitative researchers can produce the basic and applied qualitative research that can

produce the evidence clinicians need to have greater confidence in their work with their patients (Crabtree & Miller, 1999; Gabbay & Le May, 2011; Stewart, Brown, Weston, McWhinney, McWilliam, & Freeman, 2003).

In the case of adapting qualitative research approaches to studying patient experience it is important to know some of the ways clinicians and clinical researchers operationalize patient experience. These indigenous perspectives in the healthcare world, such as patient preconceptions of treatment and patients' perceptions of their quality of life, are quite amenable to qualitative approaches. For example, if a researcher is interested in taking a discovery-oriented posture to learn patients' perspectives on a naturally-occurring event in primary healthcare such as a yearly physical examination, then a qualitative design and methodology might seem a fitting selection to guide this exploration. If this is the pathway an investigator deems the best choice given the research goals and objectives, then there are a variety of designs from which to select to organize the qualitative investigation into patient experience.

## 1. Primary Qualitative Research

**Defined:** Primary Qualitative Research involves conceptualizing and conducting studies of qualitative data generated and collected for that particular study's research question or hypothesis. These studies can involve a variety of goals (e.g., description, analysis, or interpretation) and styles (e.g., scientific, artistic, clinical, or commercial); and they can be grouped into two methodological categories: (a) Generic (e.g., qualitative data analysis or case study) or (b) Designer Methodology (e.g., ethnography, grounded theory, phenomenology, narrative inquiry; Sandelowski, 2000).

**Key Source:** Marshall, C., & Rossman, G. B. (2006). *Designing qualitative research* (4th ed.). Thousand Oaks, CA: Sage.

**Patient-Focused Example:** Costello, J. (2001). Nursing older dying patients: Findings from an ethnographic study of death and dying in elderly care wards. *Journal of Advanced Nursing*, 35(1), 59-68.

## 2. Qualitative Evaluation

**Defined:** Qualitative Evaluation Design consists of a number of methodologies designed to appraise human activities systematically and formally; to determine effectiveness; to improve functioning of an organization, program, or product; or to solve problems. Qualitative Evaluation can be formative or summative in nature with particular relevance when it comes to explaining *how* specific interventions or programs actually achieve (or fail to achieve) their desired outcomes. Qualitative Evaluation can make it possible to examine the nature of process-outcome relations, identify unintended consequences, establish causal mechanisms, and map out the temporal dimensions of critical events. Qualitative Evaluation approaches can include those which incorporate generic qualitative research methods (e.g., focus groups and participant observations) into specialized methods such as Qualitative Evaluation, Constructivist (a.k.a. Fourth Generation) Evaluation; Deliberative Democratic Evaluation, and Utilization-Focused

Evaluation; those which involve more participatory methods such as Action Research, Participatory Action Research, or Appreciative Inquiry; and those which employ mixed-method designs (Shaw, 1999).

**Key Source:** Patton, M. Q. (2002). *Qualitative research & evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.

**Patient-Focused Example:** Egbunike, J. N., Shaw, C., Bale, S., Elwyn, G., & Edwards, A. (2008). Understanding patient experience of out-of-hours general practitioner services in South Wales: A qualitative study. *Emergency Medicine Journal*, 25, 649-654.

### 3. Collaborative Inquiry

**Defined:** Collaborative Inquiry Design allows investigators to focus on bringing about change, action, or improvement in a system; facilitating cooperative and collaborative process; and addressing social injustice by engaging participants as collaborative co-investigators including making key design decisions throughout the project so the endeavor is conceptualized and operationalized as doing research “with” people as compared research “on” people. These collaborative approaches include Action Research, Participatory Action Research, Appreciative Inquiry, and Human Inquiry. This style of design typically involves qualitative data collected and analyzed throughout stages or cycles of inquiry. For example, Stage One can be a Planning Phase wherein the participants determine goals and objectives along with their methods of inquiry; Stage Two can be an Action Phase wherein the participants develop and implement the planned activities; Stage Three can be an Observation Phase wherein the participants appraise the processes and outcomes of the action steps; and the Fourth Stage can be a Reflecting Phase wherein the participants contemplate the progress made, make needed changes, and decide whether or not to engage in another cycle of the project (Stringer, 2007).

**Key Source:** Whitney, D., & Trosten-Bloom, A. (2003). *The power of appreciative inquiry: A practical guide to positive change*. San Francisco, CA: Berrett-Koehler.

**Patient-Focused Example:** Abma, T. A. (2006). Patients as partners in a health research agenda setting: The feasibility of a participatory methodology. *Evaluation & the Health Professions*, 29(4), 424-439.

### 4. Mixed Method

**Defined:** Mixed Method Designs help investigators combine qualitative and quantitative data and analysis to explore a variety of research questions. In taking this pragmatic and pluralistic approach to methodology, these researchers attempt to maximize the strengths of both quantitative and qualitative methodologies while minimizing their weaknesses. The variety of mixed-method designs includes (a) sequential strategies wherein investigators conduct a series of studies featuring qualitative



or quantitative alternatively (e.g., open-ended qualitative interview results leading to the development of a close-ended quantitative questionnaire); and concurrent strategies wherein investigators include both qualitative and quantitative data collection and analysis to produce multiple perspectives on a phenomenon or to triangulation the results of the data analysis. Mixed Method designs can also be differentiated by those studies in which either qualitative or quantitative methodologies dominate the design or those investigations in which the two methodology types share the major focus (Hesse-Biber, 2010).

**Key Source:** Teddlie, C., & Tashakkori, A. (2009). *Foundations of mixed methods research: Integrating quantitative and qualitative approaches in the social and behavioral sciences*. Thousand Oaks, CA: Sage.

**Patient-Focused Example:** Small, N., Green, J., Spink, J., Forster, A., Lowson, K., & Young, J. (2007). The patient experience of community hospital: The process of care as a determinant of satisfaction. *Journal of Evaluation in Clinical Practice*, 13, 95–101.

## 5. Qualitative Meta-Study

**Defined:** Qualitative Meta-Study Designs help investigators to systematically review primary qualitative research studies in order to integrate findings to reach a new theoretical or conceptual level of understanding and development, to produce findings that are more than the sum of parts of the individual primary research studies, to create inferences derived from findings as a whole, and to generate new higher-order interpretations. In these designs the investigators can focus on reviewing (a) effectiveness of interventions, programs, and policies; (b) observational associations between interventions and outcomes; (c) prevalence of problems or conditions; or (d) subjective experiences about meanings, processes, interventions, or methodological issues. Varieties of Qualitative Meta-Studies include Meta-Ethnography, Grounded Formal Theory, Meta-Study, Meta-Summary, and Qualitative Meta-Synthesis. Basic procedures in these designs include Determine Focus of Meta-Study, Formulate Research Question, Select Meta-Study Design, Develop Proposal, Select and Appraise Articles, Extract Key Information, Conduct Meta-Data-Aggregation or Synthesis, Conduct Quality Control, and Present Findings (Sandelowski & Barroso, 2007).

**Key Source:** Paterson, B. L., Thorne, S. E., Canam, C., & Jillings, C. (2001). *Meta-study of qualitative health research*. Thousand Oaks, CA: Sage.

**Patient-Focused Example:** Khan, N., Bower, P., & Rogers, A. (2007). Guided self-help in primary care mental health: Meta-synthesis of qualitative studies of patient experience. *British Journal of Psychiatry*, 191, 206-211.

## Utilization of Five Preeminent Qualitative Methodologies to Study Patient Experience

Qualitative research presents clinical researchers with a variety of methodologies which support discovering new information, learning insiders' experiences, and exploring complex and natural phenomena like medical encounters. To these ends, qualitative methodologies prescribe rigorous means for collecting, processing, analyzing, and presenting data, information, and knowledge in clinical research such as the study of patient experiences. Some of the major qualitative methodologies that can prove quite useful in patient-focused studies include

### 1. Descriptive Qualitative Research

**Defined:** Descriptive Qualitative Research is a type of qualitative research wherein researchers use “generic” qualitative methods (e.g., interviewing, open coding, constant comparison) to produce conceptual categories and themes. Descriptive Qualitative Research

- Is basic, naturalistic, discovery-oriented descriptive research
- Offers a comprehensive summary of an event in the everyday terms of event insiders
- Stays closer to the data and to the surface of words and events than researchers conducting explanatory studies
- Is less interpretive and transformative of the data than designer approaches such as phenomenology or grounded theory
- Consists of “eclectic design” consisting of usual sampling strategies (e.g., purposeful and saturation), data collection (e.g., open-ended interviews), data analysis (e.g., categorization), and re-presentational techniques (e.g., categories with exemplary quotes; Sandelowski, 2010)

**Key Source:** Merriam, S. B. (2009). *Qualitative research: A guide to design and implementation*. San Francisco, CA: Jossey-Bass.

**Patient-Focused Example:** Kamphuis, H. C. M., Verhoeven, N. W. J. M., de Leeuw, R., Derksen, R., Hauer, R. N. W., & Winnubst, J. A. M. (2006). ICD: A qualitative study of patient experience the first year after implantation. *Journal of Clinical Nursing*, 13, 1008–1016.

### 2. Phenomenology

**Defined:** From its philosophical origins, phenomenology is group of qualitative research methodologies that helps investigators to study people's experiences in terms of how people make meaning in their lives by examining relationships between what happened and how people have come to understand these events. The distinguishing features of these phenomenological approaches (e.g., Classical - Husserl - emphasizing the essence of consciousness; Existential – Heidegger – emphasizing Dasein or “Being-

in-the-world,” Hermeneutic – Gadamer – emphasizing interpretive structures of experience of texts, Empirical – Giorgi - emphasizing descriptions of the co-researcher, and Interpretive – Smith – emphasizing that the study of a person’s lived experience involves a process of interpretation by the researcher) include

- Long interviews
- Facticity and Meaning
- Epoché
- Phenomenological Reduction: Bracketing, Horizontalization, Delimited Horizons, Invariant Qualities and Themes, Individual Textural Descriptions, and Composite Textural Descriptions
- Imaginative Variation: Vary Possible Meanings, Develop Structural Themes, Individual Structural Descriptions, Composite Structural Descriptions, and Synthesis of Composite Textural and Composite Structural Descriptions
- Member Checking and Peer Debriefing (Moustakas, 1994)

**Key Source:** Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretive phenomenological analysis: Theory, method, and research*. London: Sage.

**Patient-Focused Example:** Ebbeskog, B., & Emami, A. (2005). Older patients’ experience of dressing changes on venous leg ulcers: More than just a docile patient. *Journal of Clinical Nursing*, 14, 1223–1231.

### 3. Grounded Theory

**Defined:** Investigators using this qualitative methodology are interested in “creating theory from the ground up” as they construct or discover theory from data. Emerging from sociological origins, the variety of grounded theory approaches (e.g., Glasserian or Classical, Straussian, Constructivist, Situational Analysis, and Post-modern) have distinguishing features including

- Inductive and Deductive Processes
- Grounded Primary and Meta-Substantive and Formal Theory
- Coding (In Vivo Codes and Imported Codes, Focused Coding,/Open Coding – Conceptualization, Axial Coding – Categorization, and Selective Coding/Theoretical Coding - Grounded Theory)
- Sampling: Purposive and Theoretical
- Analysis: Memoing and Constant Comparative Method (Charmaz & Bryant, 2007)

**Key Source:** Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: Sage.

**Patient-Focused Example:** Simon, J., Murray, A., & Raffin, S. (2008). Facilitated advance care planning: What is the patient experience? *Journal of Palliative Care*, 24(4), 256-264.

#### 4. Ethnography

**Defined:** Ethnography, “the act of writing about people,” is a group of qualitative methodologies with anthropological and sociological origins by which investigators focus on Cultural Description (Cultural Orientation, Cultural Know-How, or Cultural Beliefs), Commentary, and Critique. Featuring a wide variety of approaches (e.g., Classical or Realist, Interpretive, Critical, Ethnomethodology, Autoethnography, Ethno drama, Cyber ethnography, Meta-ethnography, and generic qualitative studies incorporating “Ethnographic Procedures,” ethnography’s distinguishing features include

- Large-scale to small-scale studies
- Intensive or Extensive Fieldwork and Fieldnotes
- Emic (“Insider”) and Etic (“Outsider”) Perspectives
- Key Actors or Informants
- Participant Observation and Ethnographic Interviewing
- Thick or Vivid Descriptions
- Taxonomies and Typologies (Fetterman, 2009)

**Key Source:** Murchison, J. M. (2010). *Ethnography essentials: Designing, conducting, and presenting your research*. San Francisco, CA: Jossey-Bass.

**Patient-Focused Example:** Kerosuo, H. (2010). Lost in translation: A patient-centred experience of unintegrated care. *International Journal of Public Sector Management*, 23(4), 372-380.

#### 5. Narrative Inquiry

**Defined:** Narrative Inquiry refers to family of qualitative research methodologies with literary, linguistic, sociological, and psychological origins that all focus on stories as a means to represent and interpret actions and experiences. These investigators utilizing these approaches such as Narrative Analysis, Life Histories, and Case Study Analysis feature accounts, stories, or narratives as both the way in which they understand their situations and re-present their results. Distinguishing features include

- Personal Accounts: Story Teller as Expert
- Time and Plot
- Contextual and Relational Perspectives
- Thematic and Structural Analyses
- Identity and Culture (Clandinin, 2007)

**Key Source:** Riessman, C. (2007). *Narrative methods for the human sciences*. Thousand Oaks, CA: Sage.

**Patient-Focused Example:** Kierans, C. (2005). Narrating kidney disease: The significance of sensation and time in the emplotment of patient experience. *Culture, Medicine and Psychiatry* 29, 341–359.

### **Conceptualize and Design Qualitative Patient Experience Research Studies**

Conducting clinical qualitative patient experience studies involves making a series of Choice Points which all must cohere together in order to produce a logical and sound study (Elliott, 2008; Elliott & James, 1989). These choices must be methodologically sound and sensitive to the patient experience phenomenon itself. Some of the major choice points regarding patient experience include:

**Type of Experience:** What aspect of the patient’s experience is the focus: Self of the Patient; Patient’s Sense of Environment; Patient’s Construction of Outcome, Process, and Progress; Patient’s Valuing of Services; Patient’s Interaction with Others; or Patient’s Illness Understandings?

**Locus of Experience:** Where do you situate the locus of the patient’s experience – internal (e.g., what are your feelings about your treatment or how have you changed as a person?) or external (e.g., what were the patient’s behaviors during the treatment program or what is different about your life?)?

**Value of Experience:** What is the value assumption guiding the inquiry – neutral (e.g., what was your experience at the clinic?), positive (e.g., what if at all did you find helpful about your experience at the clinic), or negative (e.g., what if at all did you find unhelpful about your experience at the clinic) perspective?

**Time of Experience:** When in the participants’ primary healthcare experience do you want to learn their perspectives - Before, During, and/or After?

**Unit of Experience:** How broadly or how narrowly do you operationalize “patients’ primary healthcare experience” – Moments, Sessions, Course of Treatment, and/or Lives?

**Authority on Experience:** Who is sought as the authority on the patients’ primary healthcare experience - Patients, Professionals, Family Members, and/or Researchers?

**Design and Methodology:** Which qualitative design and methodology will best provide you with the context and structure to help you conceptualize, conduct, and complete the patient experience study you envisioned?

As you contemplate your choices across these various patient experience choice points, you can begin to formulate your decisions on the following ten steps for conducting a patient-focused clinical qualitative research study.

### **Ten Steps for Conducting a Clinical Qualitative Primary Research Study on Patient Experience**

The following list is intended as a general set of guidelines for researchers to plan and execute a clinical qualitative research study on some aspect of the patient's experience. Investigators following specific clinical research approaches such as conducting clinical trials of behavioral treatments (e.g., Rounsaville, Carroll, & Onken, 2001) or synthesizing qualitative research findings (Sandelowski & Barroso, 2007) would be guided by more particular prescriptions, but as suggested by these guidelines, there are some actions which are common across most-if not all-research projects, including clinical ones (Munhall & Chenail, 2007).

**1. Reflect on what interests you about patient experiences in primary health care.** Think about which aspect of patient experience you would like to learn more. Is it Patient Preconceptions, Treatment Experiences, Quality of Life, Satisfaction, Illness Understandings, or Design?

**2. Draft a statement identifying your preliminary patient experience area of interest and justifying its clinical importance.** Compose a simple sentence or two in which you state your beginning patient experience area of curiosity and explain why the topic is significant, clinically relevant, and worthy of study. By doing so you begin to address the “so what” question right away. For instance, if you select “patients’ preconceptions of their treatment” as your preliminary area of interest, you might cite demographics on patients seeking the type of treatment in your proposed study as reasons why the topic would be worthy of further study. In addition, reflect upon your personal standpoint in relation to your preliminary area of interest and record your hopes, aspirations, and biases. As you progress through the rest of these steps, refer back to this record from time to time in order to assess if any of your personal perspectives are negatively shaping the research process (e.g., biasing data analysis or research design).

**3. Hone your patient experiences focus (Locus, Value, Time, Unit, and Authority Choice Points).** Now that you have begun to articulate the type of patient experience, begin to hone your focus by considering the choices regarding perspectives on patient experience you will need to make in order to design your study (Elliott, 2008; Elliott & James, 1989). For example, if you have selected “patients’ preconceptions of their treatment” as your topic, explore the options you can use to focus your study by deliberating on the Locus, Value, Time, Unit, and Authority Experience Choice Points as described above.

**4. Compose your initial patient experience inquiry research question or hypothesis.** Based upon your answers to the experience questions in Step Three, compose your initial research question or hypothesis for your study. For example, one

research question could be, “What are male patients’ positive and negative preconceptions regarding a routine colonoscopy?” In composing this research question, envision what would be the clinical implications arising from the results of this study. How would the results benefit researchers, clinicians, patients, and their families?

**5. Define your goals and objectives.** Focus on the overall goals of your potential research study and the objectives that you must accomplish in order to achieve these goals. For example, if a goal is to learn more about patient preconceptions regarding a routine colonoscopy, relevant objectives could be (a) Conduct a literature search in order to learn what has been previously published on this topic, (b) Adjust the research question based upon the literature review, (c) Identify potential sites for collecting data, (d) Prepare Institutional Review Board (IRB) protocol, etc. Make sure each goal and objective can be measured so you can track the progress you are making and identify where problems are arising.

**6. Conduct a review of the relevant patient experience literature.** Some researchers start their research process with a review of the literature, some delay their reviews until after the study is completed, and some continually review the literature throughout the research process. Some researchers explore the literature to learn what is known about a phenomenon in question and then formulate hypotheses which will guide a confirmatory-oriented inquiry to test whether or not evidence can be established supporting or rejecting what is believed to be known about the phenomenon in question. Some researchers explore the literature to learn what is not known about a phenomenon and then formulate questions which will guide a discovery-oriented inquiry to uncover new evidence about the phenomenon in question. With any of these approaches it is important that the researcher identify key terms (e.g., patient preconceptions, colonoscopy, cancer risks, etc.) to guide the electronic searches of relevant databases (e.g., ProQuest, Medline, and Google Scholar); in addition, the researchers must complement electronic searches with systematic reviews of the references cited in the articles collected to locate additional sources.

**7. Develop your study design.** Develop a research design which will allow you to address your research question or hypothesis effectively and efficiently. To do so you will need to make choices in the following areas:

- **Participants:** Who will participate in the study, how will I gain access and recruit them, and what precautions will I need to take in order to protect them from harm throughout the study?
- **Research Design and Methodology:** What will be my research design and methodology (e.g., descriptive, ethnography, mixed methodology, action research, or grounded theory); what will be the epistemological orientation (e.g., objectivism, constructionism, or subjectivism) and theoretical perspective (e.g., post-positivism, interpretivism, critical theory, or postmodernism) for my methodology; and what will be my procedures for generating, collecting, preparing, and analyzing the data (Crotty, 1998)?

- **Quality Control:** How will I maintain rigor (e.g., reliability, validity, trustworthiness) throughout the study?

**8. Conduct a self-assessment in order to determine what strengths you have that will be useful in your patient experience study and what skills you will need to develop in order to complete your study.** Review your plan and identify what skills and knowledge base you will need to complete the study successfully. Develop a growth plan for helping you to master the competencies you will need throughout the study (e.g., open-ended interviewing, taking field notes, using statistical packages, writing, etc.). You may also consider creating a team or involve consultants to assist with your areas in need of development. Remember to reflect upon your personal context and point-of-view which may bias you during the study and record your plan for managing this perspective throughout the project.

**9. Plan, conduct and manage the patient experience study.** Develop an action plan detailing the steps you need to take in order to begin and complete your patient experience study. Depending on the study, the elements you will need to address include: people (including yourself), communication, data (including back-up systems), analysis, results, technology, time, money, ethical concerns (including securing institutional approvals), and other resources. Maintain a chronicle of your research activities (e.g., lab notebook, journal, diary, audit trail, and time and effort reports) and save supporting documentation.

**10. Compose and submit your report.** Depending on the vehicle you will use to report your patient experience study (e.g., dissertation, thesis, scholarly paper, poster, or conference presentation), identify the relevant policies and rules governing the form, substance, and submission of the report (e.g., school or departmental guidelines, journal article submission requirements, book prospectus elements, style manual of the American Psychological Association, 2010, etc.) and report and submit your findings in compliance with these parameters. Even though there can be a variety of outlets to make the results of your study public, a typical reporting APA format would be as follows:

- **Title**
- **Author Name and Institutional Affiliation**
- **Author Note**
- **Abstract**
- **Key Words**
- **Introduction**
  - Introduce the problem
  - Explore the importance of the problem
  - Describe the relevant previous research
  - State research question(s) and fit with research design
- **Method**
  - Data Set Criteria
  - Data Selection and Sampling
  - Data Set Description



- Procedures: Data Processing and Analysis
- Quality Control
- **Results**
- **Discussion**
  - Interpret the results in the context of your research question and the relevant literature
  - Acknowledge the limitations of the study
  - Describe the significance and implications of the study
- **References**
- **Appendices**

It is important to think about the form in which you will present your study early and often so you do not wait until the end of your study to write up your report. Lastly, be prepared to write and re-write your report a number of times until you have successfully represented the process and outcome of your research project.

To help you continuously improve your drafts, you can also use the following qualitative research appraising tools to assist you in the writing and revising process:

Critical Appraisal Skills Programme (CASP). (2006a). *10 questions to help you make sense of qualitative research*. Oxford, England: Milton Keynes Primary Care Trust. Retrieved from <http://www.sph.nhs.uk/sph-files/casp-appraisal-tools/Qualitative%20Appraisal%20Tool.pdf>

Critical Appraisal Skills Programme (CASP). (2006b). *10 questions to help you make sense of reviews*. Retrieved from <http://www.sph.nhs.uk/sph-files/casp-appraisal-tools/S.Reviews%20Appraisal%20Tool.pdf>

Tools like the CASP ones make for excellent guiding systems because they reflect some basic elements that are typically built into qualitative reports. At the same time, the CASP instruments are not method-specific so it is always recommended that the tool be paired with the main method source you used to organize your designing process so you can have more pertinent guidance for your particular design and method.

## **Discussion**

The challenge of conducting any research study successfully is to manage choices well throughout the inquiry. In starting a study you will quickly realize that one decision made usually opens up multiple new decisions which you will also have to address. For example, if you select a primary qualitative research design for your patient experience study, you will then have to decide which primary qualitative research methodology will best fit your clinical research question. Then if you select grounded theory (Glaser & Strauss, 1967), the next choice you will need to figure out is what style of grounded theory works for the project. If you have chosen the Glaser variation (Glaser, 1994), you then will need to work on how you will actually carry out your clinical Glaserian grounded theory study on patient experience.

In making these methodological decisions it is critically important that you document your actions and evaluate them to make sure that your choices made over time form a coherent plan. Refer regularly back to your research question and study plan to make sure that you are staying on track. Of course you can make adjustments to your plan along the way; however, make sure you are aware when such calibrations need to be made; otherwise your study will quickly go off track. In managing these clinical qualitative research studies, your best guide is your research question. Consult it often so you keep your methodological decision-making process coherent and you end up investigating the patient experience phenomenon you started out to explore, thus moving one step closer to contributing critically important knowledge to the practice of patient-centered healthcare.

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