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# Nigerian Cancer Survivors' Perceptions of Care Received From Health Care Professionals

Olusegun Akinsuli  
*Walden University*

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# Walden University

College of Health Sciences

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Olusegun Akinsuli

has been found to be complete and satisfactory in all respects,  
and that any and all revisions required by  
the review committee have been made.

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2016

Abstract

Nigerian Cancer Survivors' Perceptions of Care Received

From Health Care Professionals

by

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MPH, University of Liverpool, 2011

MB, University of Ibadan, 1989

BS, University of Ibadan, 1989

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Health

Walden University

August 2016

## Abstract

Cancer patients worldwide receive care from multidisciplinary teams, and patients sometimes have little or no knowledge about the different treatment options available, making communication with their care providers an important influence in how they perceive their care. Patient satisfaction with care is an important factor in determining survivorship. The increasing prevalence of cancer worldwide has become a huge public health issue. The World Health Organization has warned that the potential gains from combatting infectious diseases in Nigeria might be lost because of the increasing prevalence of cancer. The purpose of this grounded theory study was to obtain the perceptions of 30 cancer survivors in Nigeria about their care in federally funded hospitals to improve cancer care in the country. Through a constructivist grounded theory (CGT) approach, data from 30 in-depth interviews with the cancer survivors were analyzed. Data analysis included open coding, selective coding, theoretical coding, and memo writing. Three themes emerged from the data analysis: positive perception of care (P), service improvement (S), and good care experience (G), all of which were cyclically related to form the PSG substantive theory, which indicates that better health care to cancer patients will improve preventative and curative cancer care services in Nigeria. This theory was validated by relating it to 3 theories in the literature as recommended in CGT research. The implication for positive social change is that the results might provide information that can help health care professionals to improve how they communicate with, relate to, and care for cancer patients and their families in Nigeria and other countries.

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## Acknowledgments

I would like to extend my gratitude to my committee members, Dr. Frazier Beatty and Dr. Chester Jones, for their guidance; to my classmates; and to my friends, whose support was a foundation of continuous inspiration and guidance. I also would like to offer special thanks to my family members, who supported me throughout my academic journey and motivated me to achieve this lofty academic goal.

## Dedication

This work is dedicated to the memory of my late brother, Johnson Akinsuli, who worked tirelessly for me to have the best education obtainable in Africa, Europe, and the United States. You gave everything for me, and you lost your life tragically when least expected.

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## Chapter 1: Introduction to the Study

### **Introduction**

In cancer care, patients are concerned about appointment wait times, the information provided by health care providers about diagnosis and treatment options, prognosis and continuity of care provided, and the interpersonal skills and empathy of their health care providers (Gupta, Rodeghier, & Lis, 2013). Health care services can be evaluated using diverse qualitative and quantitative methodologies, including longitudinal surveys, in-depth interviews, focus groups, patient panels, consultations with voluntary groups, and analyses of patient feedback and concern (Gupta et al., 2013). This study was designed to explore the perspectives of cancer survivors in Nigeria regarding the care that they received from their health care providers using a qualitative methodology with a constructivist grounded theory (CGT) approach.

This study was designed to generate results that will facilitate modifications in the delivery of care, such as in hospital protocols and operations (Gupta et al., 2013). The results also were intended to facilitate the development of a health care system based upon the different care needs of cancer patients. Another planned outcome of the study is to improve the perceptions of society toward cancer patients by helping to disseminate information about difficulties in various aspects of care and management that could result in attitudinal changes toward cancer patients.

Cancer patients are known to be more satisfied if their care involves the provision of emotional support, reductions in physical discomfort, and respect for their preferences (Gupta et al., 2013; Wildes, Miller, Miguel de Majors, Otto, & Ramirez, 2011). These

factors are important because self-reported satisfaction with health care has been associated with lower mortality rates among cancer patients (Gupta et al., 2013). Information on patients' satisfaction is used by health care providers to identify areas requiring improvement, benchmark and compare hospitals, and market strategies by health care providers (Lis, Rodeghier, & Gupta, 2009). Recent advances in all aspects of cancer care and the use of multidisciplinary teams (MDTs) makes the provision of care very complex and the need to know how patients perceive their care very important (Lis et al., 2009).

I selected the Hall Satisfaction Index to track patient satisfaction; this index was developed by Hall, Griffiths, and McKenna (2013) to assess satisfaction with health care providers, including doctors, nurses, and social workers. The index is based upon items that assess overall satisfaction with health care providers; the amount of time spent with health care providers; relief of worry; and communication, humaneness, and technical competency of health care providers (Wildes et al., 2011). The Institute of Medicine's (IOM) 2011 report on the quality of health care in the United States led to an accelerated quest for improved cancer care (as cited in Ferrel, McCabe, & Levitt, 2013; Nekhlyudov, Levit, Huria, & Ganz, 2014). In 2013, the IOM developed a framework for the provision of high-quality cancer care in the United States (as cited in Ferrel et al., 2013). The 2014 IOM report addressed the quality of care for cancer care along a continuum that ranged from early diagnosis to treatment, long-term survivorship, and end-of-life (EOL) care (Ferrel et al., 2013; Nekhlyudov et al., 2014). In the same report, the IOM recommended that cancer care teams provide cancer patients and their families with adequate and easily

understood information about their diagnosis, prognosis treatment benefits and adverse effects, availability of palliative care, and estimates of the direct and indirect financial burden of cancer (as cited in Ferrel et al., 2013; Nekhlyudov et al., 2014).

### **Background of the Study**

The incidence of cancer is increasing worldwide, and costly interventions are concomitantly impacting the ability of health care systems to respond (Ferrel et al., 2013; Nekhlyudov et al., 2014). The quality of cancer care is therefore a critical component of the quality of all health care systems, which is why the IOM has recommended that affordable, accessible, and evidence-based cancer care be used to fully engage patients and their families in all of the different aspects of the cancer care continuum (as cited in Ferrel et al., 2013; Nekhlyudov et al., 2014). The IOM recommended that the U.S. Department of Health and Human Services fund competence development programs for health care providers who are involved in providing cancer care (as cited in Ferrel et al., 2013).

Cancer care in most parts of the world is delivered by MDTs (Taylor, Finnegan-John, & Green, 2014). Individual cases are discussed at MDT meetings in order to plan the most appropriate care for the patients (Taylor et al., 2014). Although there has been abundant discussion in the literature about the benefits of using MDTs, patients are rarely involved in the decisions taken by the MDTs (Taylor et al., 2014). In the United Kingdom, for example, the involvement of patients in decisions about their care is mandated by the National Health Service (NHS; Taylor et al., 2014). The NHS has recommended that health care providers understand the perspectives of patients because



of an ethical imperative to involve them in decisions about their care and the wide range of clinical benefits (Taylor et al., 2014). Patient-centered care (PCC) is a critical component of high-quality care, so patients should have the right and ability to provide input into the decisions made by MDTs (Lamb et al., 2014).

The treatment of cancer has become a complex process involving numerous health care practitioners; in addition, newer frontiers of treatment rely on high-tech pharmaceutical products (Gagliardi et al., 2014; Nekhlyudov et al., 2014). Reliance on multiple clinicians poses real challenges in terms of deficiencies in care communication and coordination (Nekhlyudov et al., 2014). Cancer care has become cost prohibitive to patients and their families, and it faces difficult challenges, despite the availability of quality health care practitioners and information technology (Nekhlyudov et al., 2014). The existing cancer care system in the United States is inadequate in many aspects of good care and has failed to meet the expectations of cancer patients and their families (Nekhlyudov et al., 2014). Cancer patients in the United States do not receive the support required to make treatment decisions that meet their needs and address their values and preferences (Nekhlyudov et al., 2014).

The level of communication between health care practitioners and cancer patients regarding diagnosis, treatment options, and effects of treatment on quality of life (QoL) is below expectations for the majority of patients in the United States (Nekhlyudov et al., 2014). The rising life expectancy in Western countries means an increased incidence of cancer after the age of 65 years and more demand for cancer care (Nekhlyudov et al., 2014). The health challenges facing the majority of cancer patients are relevant not only

to the effects of the disease and the treatment protocols but also to comorbid cognitive impairment, chronic metabolic disorders, chronic respiratory disorders, and chronic cardiovascular disorders that affect the QoL of these patients (Gagliardi et al., 2014; Nekhlyudov et al., 2014).

It is important to understand the experiences of cancer patients to improve communication with them. Cancer patients face significant physical and emotional challenges that often are exacerbated by nonideal communication with their health care providers (Teno, Lima, & Lyons, 2009). Lapses in the delivery of care can be prevented through more effective communication between clinicians and patients that reduces the risk of harm (Peppercorn et al., 2011). PCC is especially important when treating patients with cancer because of the high levels of morbidity and mortality associated with cancer diagnosis (Peppercorn et al., 2011). However, when health care professionals do not provide appropriate answers to cancer patients, these patients become confused about their diagnoses, prognoses, treatment plans, and side effects and benefits of treatment (Nekhlyudov et al., 2014; Wagner et al., 2010). This situation affects the quality of care delivered to cancer patients (Wagner et al., 2010).

It is essential to explore the perceptions of cancer patients about the delivery of their care and the factors that influence these perceptions. There is a gap in research on the care requirements of cancer patients, resulting in poor knowledge of these care requirements by health care providers (Nekhlyudov et al., 2014; Wagner et al., 2010). This study adds to the current knowledge base regarding the perceptions of cancer

patients about their care and provides insight into the experiences that precipitated these perceptions.

### **Problem Statement**

The World Health Organization (as cited in Eguzo & Carmazine, 2013) projected that the incidence of invasive cancer in Nigeria and other developing countries will increase as the number people in these developing countries increasingly survive infectious diseases such as malaria, gastroenteritis, and tuberculosis. This prediction means that more Nigerians will seek cancer care from health care professionals for early diagnostic and therapeutic treatment over the next 3 decades and beyond (Nekhlyudov et al., 2014; Walsh et al., 2011). This cancer treatment, if it follows current models, will be delivered by MDTs comprising health care specialists in fields such as oncology, radiotherapy, chemotherapy, immunotherapy, histopathology, physiotherapy, public health nursing, palliative care, and general family practice (Gagliardi et al., 2014; Nekhlyudov et al., 2014; Walsh et al., 2011).

This MDT approach has led to increased concern about the care being provided to cancer patients (Gagliardi et al., 2014). With the increasing complexity of cancer care, it has become imperative to coordinate care among health care professionals, caregivers, and patients (Gagliardi et al., 2014). Therefore, the health outcomes of cancer patients can impact their opinions about the care delivered by their health care providers.

The need for effective communication between health care providers and cancer patients has become a priority because the experience of cancer is fraught with uncertainty, anxiety, fear, and questions about quality of care (Nekhlyudov et al., 2014;

Stajduhar, Thorne, McGuinness, & Kim-Sing, 2010; Wildes et al., 2011). Cancer patients experience elevated levels of stress while interpreting complex information and making life-altering medical decisions (Wildes et al., 2011). In most countries, MDTs meet to discuss the care of their cancer patients, and they make treatment decisions that often do not involve any input from the cancer patients themselves, who basically become disenfranchised participants in their care (Taylor et al., 2014). The intention of this study was to close the gap in the literature pertaining to the experiences of cancer patients because how patients perceive the quality of their care and the competencies of health care providers is unknown.

### **Purpose of the Study**

The purpose of this study was to explore the perceptions of cancer survivors in Nigeria regarding the care received from health care professionals. I wanted to understand their experiences to develop a theory based upon the data obtained. I intend to disseminate the results in an effort to improve the skills and competency of health care professionals in the delivery of cancer care. I used the research paradigms of constructivism and critical humanism, a subtype of the interpretive paradigm, to interpret the experiences of patients in various stages of cancer, in accordance with the guidelines of Creswell (2007) and Rudestam and Newton (2007). I observed cancer survivors in their cultural and social contexts using these paradigms to interpret the experiences described by the cancer survivors themselves, in alignment with Creswell (2007, 2009).

## **Research Aims and Objectives**

The focus of this study was to explore the perceptions of cancer survivors about the delivery of health care services. The study had the following objectives:

- To gain the perceptions of cancer survivors about different methods of cancer care.
- To obtain the perceptions of cancer survivors about the different factors that determined the quality of care that they received.
- To develop a theory based upon the experiences of cancer survivors while they were receiving care by using the CGT described by Charmaz (2014).

## **Research Question and Subquestions**

### **Primary Research Question**

I conducted the study using a CGT approach to generate a theory based upon the data collected from the participants, as recommended by Creswell (2009). The study was guided by one overarching research question (RQ): What are the perceptions of cancer survivors in Nigeria about the care delivered by their health care practitioners? This central RQ led to the generation of subquestions that had direct implications for the data generation and analysis procedures (Creswell, 2009; Rudestam & Newton, 2007).

### **Subquestions**

1. How do major indices of survivors' perceived quality of cancer care indicate positive or negative perceptions toward the care?
2. What do cancer survivors perceive as the desired goal of their care?
3. How do cancer survivors perceive the way through which the desired goals of their care were achieved?

4. What factors contribute to the different levels of survivors' perceptions about the care received from health care providers?
5. How can survivors' perceptions about the care received from health care providers be improved?

### **Theoretical Foundation**

Because no appropriate theories are available on this topic, I selected a qualitative approach to develop a theory based upon the empirical data collected from the participants related to time, place, culture, and context, as well as my position (Glaser & Strauss, 2009). I selected the CGT approach of the classical grounded theory (GT) to conduct this study (Higginbottom & Lauridsen, 2014; Johnson, 2014). The GT was developed in 1967 by Glaser and Strauss (2009) to facilitate the generation of theories of human behavior from experiential data and used to study the treatment of dying patients in hospitals and clinics in the United States. This theory uses constant comparisons that involve contrasting collected data with preexisting concepts and notions (Higginbottom & Lauridsen, 2014; Urquhart, 2013). This constant comparative and theoretical sampling approach is widely used in nursing, public health, and social science research, and involves checking and revising emerging theories or models against additional data from individual participants or from a combined pool of data from all participants (Creswell, 2009; Higginbottom & Lauridsen, 2014; Rudestam & Newton, 2007).

Grounded theory research has three approaches, depending on the ontological and epistemological stance of the researcher (Higginbottom & Lauridsen, 2014). The systematic approach, also known as the Straussian school of thought, uses predetermined

categories to make explicit connections (Creswell, 2007, 2009; Higginbottom & Lauridsen, 2014). The emergent approach, also known as the Glaserian school of thought, explores social processes without preset categories (Creswell, 2007, 2009; Higginbottom & Lauridsen, 2014). The social constructivist approach focuses on the subjective meanings of the participants and makes explicit the beliefs and experiences of the researcher; it produces suggestive and tentative conclusions (Creswell, 2007, 2009; Higginbottom & Lauridsen, 2014). Because the RQ was designed to develop a sound theory to identify what influenced the perceptions of cancer survivors in Nigeria about their care, I selected the CGT approach as the most appropriate choice. This decision was based upon the CGT explanation of data and theories as being neither discovered nor emergent, and instead being interactively constructed by study participants and researchers to understand the meanings of the participants' experiences (Creswell, 2007, 2009; Higginbottom & Lauridsen, 2014).

This design choice acknowledged my interpretive role biases and perspectives, as suggested by Higginbottom and Lauridsen (2014). The flexible and creative nature of the CGT was the best design for the study because it is congruous with my own ontological and epistemological philosophies, as suggested by Higginbottom and Lauridsen. The design reflected my belief that knowledge is developed only through socially mediated, context-dependent, and culturally constructed processes, as suggested by Higginbottom and Lauridsen. The individual interviews and the theoretical group interviews gave me a diversity of perspectives to achieve this goal of advancing knowledge while giving voice to the participants, as suggested by Higginbottom and Lauridsen. This design

acknowledged my subjectivity and interactive relationship with the participants as we created new knowledge through an inquiry-driven research process, as suggested by Higginbottom and Lauridsen as well as Johnson (2014).

Finally, in this constructivist approach, data analysis occurs simultaneously with the collection of more data from interviews, observations, and memoranda or field notes (Creswell, 2007, 2009; Rudestam & Newton, 2007). The process of data collection and analysis ends when data saturation is reached (Creswell, 2009). This is the point at which the substantive theory emerges (Stone, 2013). The substantive theory at the end of a study emerges from the data as a result of the combined processes of constant comparisons and interpretation of emerging themes and theoretical concepts (Johnson, 2014). The substantive theory emerging at the end of these processes in the current study was the sum total of my understanding of how the cancer survivors created their own meanings of reality (Ghezeljeh & Emami, 2009).

Following the CGT approach ensured that the data collected from the participants would drive the construction of a strong theoretical foundation in response to the RQ and the subquestions (Johnson, 2014). I chose the CGT because the topic, aims, and objectives of the study required the incorporation of the exact words and interpretations of these cancer survivors and the fact that I had practical knowledge about the issues facing cancer care services Nigeria (Johnson, 2014).

### **Nature of the Study**

I conducted this study using a qualitative methodology with a conceptual framework, that is, the CGT approach, which emphasizes that the data collection, data



analysis, and theory were constructed by the researcher and that the role of the researcher and the participants contextualized accurate interpretations, subjectivity, and reflexivity (Johnson, 2014). This was an inductive approach to research (Creswell, 2009; Higginbottom & Lauridsen, 2014). I used this qualitative methodology to understand the cancer patients' experiences, which were not based upon any current theories or research paradigms (Creswell, 2009; Johnson, 2014; Rudestam & Newton, 2007). Instead, I obtained my data based upon the experiences of survivors in Nigeria who had received care for the treatment of cancer.

This qualitative approach facilitated the analysis of the empirical data from purposively selected participants by comparing the data with emerging theories and including more participants until data saturation had been reached (Creswell, 2009; Johnson, 2014). The analysis of empirical data involves a three-tier coding process: open, selective, and theoretical coding. Open coding allowed me to generate large categories of themes. In selective coding, I selected and positioned each large thematic category within a theoretical model. In theoretical coding, I joined the different theoretical categories to form a theory model on how cancer survivors in Nigeria viewed their care based upon data generated from their experiences as survivors of cancer (Creswell, 2007; Higginbottom & Lauridsen, 2014).

Cancer patients consider the ability of health care providers an important parameter in determining the adequacy of the care delivered to them (Kvåle & Bondevik, 2010). I collected the data by conducting individual in-depth interviews with each of the initial six participants. The interviews were about 45 minutes long. They were followed

by further data collection and analysis through constant comparisons and theoretical sampling until data saturation was reached after 30 such interviews. The emerging codes and theoretical concepts formed the foundation of the theoretical model about the ways in which the cancer survivors perceived their care. Finally, theoretical group interviews were conducted with the 30 participants recalled in five small groups of six participants in order to expand on, modify, and verify the emerging theoretical concepts (Morse, 2007).

### **Definitions of Terms**

*Autonomy of decision making:* Autonomy refers to the ability and right of patients to be involved in decisions about their health care (Karlsson, Milberg, & Strang, 2012). It has been conceptualized as the preferred method for understanding the choices, values, and preferences of patients to promote their autonomy (Epstein & Street, 2011a).

*Axial coding:* A stage of coding usually between selective coding and theoretical coding. I omitted this stage of coding because it commonly poses challenges to researchers and was omitted in the CGT.

*Coding:* The act of attaching concepts to data in grounded theory analysis (Urquhart, 2013).

*Competence:* The capability of health care professionals to deliver care to patients from diverse backgrounds. It ensures that patients receive care appropriate to their needs (Saha et al., 2013). This high-quality care must be patient and family centered, equitable, evidence based, and safe (Weech-Maldonado et al., 2012).

*Constant comparison:* A method in CGT analysis in which one piece of data that has been attached to a concept is compared to another piece of data that has been attached to the same concept to determine whether it represents the same concept. This process helps to refine the emerging concepts (Charmaz, 2014; Urquhart, 2013).

*Constructivist grounded theory:* A modern version of grounded theory that still uses methods such as coding, memo writing, and theoretical sampling of the classical grounded theory but with a shift in its epistemological foundation. Researchers who use this method seek an abstract understanding of the studied lives of the participants and view this analysis as located in time, place, and the situation of inquiry (Charmaz, 2014).

*Open coding:* The first stage of coding in the CGT; the data are examined line by line, and codes attached to words or groups of words (Urquhart, 2013).

*Patient-centered care (PCC):* According to Epstein and Street (2011b), PCC is based upon the awareness of health care professionals that patients are individuals who have the right to receive care delivered in accordance with their own social contexts. They must be listened to, respected, informed, and involved in their own care. PCC is further based upon the delivery of care to patients in consideration of their cultural and social beliefs (Gupta et al., 2013; Tucker, Marsiske, Rice, Nielson, & Herman, 2011).

*Selective coding:* The second stage of coding in the CGT; codes are grouped into higher level categories (Urquhart, 2013)

*Shared decision making:* In this approach to care, patients and their health care providers share the best available evidence when making decisions; patients receive support while considering options in order to make informed choices (Elwyn et al., 2012).

*Theoretical coding:* This is the final stage of coding in the CGT; relationships are built between categories by using theoretical codes (Urquhart, 2013).

*Theoretical group interviews:* These are small discussion groups used in the CGT approach to complete the data analysis. These groups help to polish the data collection, complete the process of data saturation, and polish the substantive theory. They are used in place of focus groups (Morse, 2007).

*Theoretical memos:* Occur when researchers take a break from data coding to write down their ideas about the different codes (Urquhart, 2013). Memo writing is important in the CGT approach because it helps the process of analysis, such as the development of codes into categories (Charmaz, 2014).

*Theoretical sampling:* A type of grounded theory sampling that follows the development of a tentative theoretical category, in which researchers seek data from participants to illuminate and define the properties and relevance of this theoretical category (Charmaz, 2014; Urquhart, 2013).

*Theoretical saturation:* This is the point in coding when no new codes occur in the data being analyzed (Urquhart, 2013).

*Theoretical sensitivity:* The ability to understand and define phenomena in abstract terms and to demonstrate abstract relationships between studied phenomena (Charmaz, 2014).

*Substantive theory:* The theory generated from the CGT in the first instance. It is related to the phenomenon being studied and is not generalizable.

### **Assumptions**

I assumed that using the CGT approach would lead to the development of a theory derived mainly from the data generated from cancer survivors and that this theory would be applicable to all current and past cancer patients. However, the diverse socioeconomic (SES) backgrounds of the cancer survivors also could have resulted in variations in the data generated from the in-depth interviews and the theoretical group interviews.

I also assumed that this methodology would generate a theory that would consider my perspectives and privileges as a primary health care physician, my interactions with the cancer survivors, and the geographical location of Nigeria as the best choice for answering the RQ (Higginbottom & Lauridsen, 2014). I assumed that PCC would be the best model for this study, regardless of the fact that the participants' perceptions of the quality of care might have been determined by factors beyond their influence that had nothing to do with the real quality of care in terms of measurable variables.

### **Scope and Delimitations**

I explored the perceptions of a sample of cancer patients in Nigeria about the effectiveness and efficiency of the care delivered to them by health care practitioners. I explored the ways in which health care practitioners could improve the provision of care to cancer patients. I chose to study the perceptions of cancer patients in Nigeria because such perceptions could serve as important predictors of disparities in the health care system (Ferrel et al., 2013; Hall et al., 2013). The sample comprised cancer survivors in Nigeria from various religious and ethnic groups, as well as from different gender, age, educational, and SES levels. At the time of initial diagnosis, the participants would have

had various types of cancer and would have been in different stages of the disease. However, they all survived their cancer and either were in remission or had been cured following treatment when the study was being developed. Individuals who did not have cancer were excluded from the study, along with individuals who had survived cancer but were not physically or emotionally fit enough to be interviewed or participate in the theoretical group interviews.

### **Limitations**

The primary limitation of the study was that the huge volume of data made it difficult for me to analyze and interpret the responses of the participants accurately, regardless of the usefulness of NVivo v.10 in organizing my data during the analysis. This process also required an extensive amount of time to analyze the transcribed responses, develop the three levels of codes to identify themes, and generate a theory (Anderson, 2010). Purposive sampling served as an important constraint in this qualitative study because nonrandom sampling limited the generalization of the findings to patients suffering from other diseases and to other research contexts (Adams et al., 2011).

Nontransferability of the data was a limitation because it was not possible for me to generalize the findings to other contexts. The responses were representative of the perceptions of cancer survivors in Nigeria relevant to their sociodemographic variables, one of which is that they live in a low-income country. Some issues related to the dependability of the findings involved the replication of the entire study over time because the participants had different cancers, meaning that their perceptions about their

care were different and unique. In addition, it might be difficult to duplicate the study because patients with other types of cancer might have different perceptions about the delivery of their care.

Another major limitation was the possibility of researcher bias during the transcription process. I addressed this limitation by reading the transcriptions of the individual interviews and theoretical group interviews many times to ensure the accuracy of my understanding and the subsequent analysis of the data. Limitations pertaining to the credibility and validity of the study were overcome through such methods as triangulation, a method of collecting data from more than one source, or more than one data collection strategy (e.g., theoretical group interviews and individual interviews; Green & Thorogood, 2009).

### **Significance of the Study**

This study will contribute to the body of knowledge regarding the ways in which cancer patients perceive their care by investigating the factors that influenced the development of these views. The findings might initiate further research into cancer care in other parts of the world. This knowledge might facilitate positive changes in the practices of health care professionals involved in the care of cancer patients.

### **Implications for Social Change**

This study might pave the way for the additional allocation of resources to cancer prevention and early diagnosis, and the care of people diagnosed with cancer. This study might encourage nongovernmental organizations (NGOs) and philanthropists to commit financial resources to cancer prevention, early diagnosis, and treatment. Finally, this

study might generate more awareness among policymakers and political leaders about the issues facing cancer patients.

### **Summary**

Disparities exist in the health care delivered to cancer patients that can influence how these patients perceived their care. The process of cancer care is complex, and it is delivered by MDTs in countries across the globe. Information related to treatment protocols often is not shared with cancer patients, who have no input into the decisions made at MDT meetings about their care. This lack of communication between cancer patients and health care professionals affects the ways in which these patients perceive their care. The experiences of cancer patients while navigating the complex cancer care system and the outcomes of their care have been predicted to influence their views (Siegel, Ma, Zou, & Jemal, 2014).

The purpose of this study was to explore the perceptions of cancer survivors in Nigeria about the delivery of their care and construct a theoretical model based upon the data obtained from the participants. I used constructivist and interpretive research paradigms in this qualitative study (Creswell, 2007). The theoretical foundation of the study was the CGT approach to qualitative research (Johnson, 2014). PCC, the conceptual framework of this study, allowed me to study the topic through the contextual lens of the sociodemographic and cultural characteristics of the cancer patients that influenced their perceptions. I used the CGT research tradition to collect empirical data from the purposefully selected cancer survivors (Creswell, 2007; Fetterman, 2010).



Chapter 2 is a review of literature related to various aspects of how cancer patients perceive their care.

## Chapter 2: Literature Review

### **Introduction**

The elements of trust and satisfactory communication between cancer patients and health care providers are important to ensure satisfactory outcomes for cancer patients. A diagnosis of cancer places a heavy emotional burden on patients and their families (Wagner et al., 2010). People receiving treatment for cancer have different perceptions of the care delivered to them by health care providers (Wildes et al., 2011). Cancer patients see the appropriateness and adequacy of the clinical knowledge, experience, and skills of the health care practitioners in charge of their care differently (Wagner et al., 2010). Understanding the perceptions of cancer patients is important to health care practitioners and policymakers (Johnson, 2014).

Gregurek, Braš, Đorđević, Ratković, and Brajković (2010), as well as Price et al. (2012), acknowledged that cancer patients experience numerous problems during diagnosis and treatment that often remain unreported. For example, cancer patients' preferences are not always considered or incorporated into their care plans (Mazor et al., 2012). Ways to improve the perceptions of patients about the health care delivered to them have been considered over the years. For example, Mazor et al. (2013) highlighted the need for sufficient communication between patients and health care practitioners during diagnosis and the early course of treatment.

The purpose of this study was to explore the perceptions of cancer survivors in Nigeria about the care delivered to them by their health care practitioners. The literature has focused on various aspects of this important issue, so in this chapter, I discuss the

strategy that I used to search for relevant studies. I also provide details about the theoretical and conceptual frameworks of those previous studies, and I review literature related to the topic of perceptions of health care delivered to cancer patients and strategies to improve the delivery of health care to cancer patients. The chapter ends with a summary of the literature review.

### **Literature Search Strategy**

By using the appropriate key terms and suitable databases, I was able to retrieve the most recent and inclusive literature. I searched databases such as PubMed, Science Direct, ProQuest, CINAHL Plus, Medline, and Google Scholar to retrieve relevant studies related to cancer survivors' perceptions of the care that they received. Key search terms were helpful in finding relevant literature. Using Boolean terms facilitated the retrieval of studies on the topic. I used the Boolean terms AND, OR, and NOT to refine the search by combining various search terms or excluding certain terms, as suggested by the Walden University Library (2014). The articles for review spanned publication dates from 1985 to 2015. Only articles written in English were searched because the relevant literature has been published in this language.

Key terms included *cancer patients*, *cancer survivors*, *health care practitioners*, *perspectives*, *patient-centered care*, *communication*, *family*, *experiences*, *perceptions*, and *psychological health*. I accessed several articles using these search criteria. I then refined my search to include only studies related to cancer patients and their perspectives about the care received from their health care practitioners. I also searched the grey

literature to obtain other information relevant to the review, as suggested by the Walden University Library (2014).

### **Theories Used in Cancer Care Research**

Although this study was based upon the CGT methodology, which means that the main purpose of the study was to generate a new theory, many studies in cancer research have been based upon existing theories. Qualitative researchers have used theories to explain behaviors and attitudes in studies or act as an orienting lens to guide the design of such studies (Creswell, 2009). The literature has many examples of studies, some described next, in which theories that have been used both ways to enhance the benefits that cancer patients derive from their care experiences. However, none of these theories satisfactorily helped to answer the RQ or subquestions on cancer care in Nigeria.

Kvåle and Synnes (2013) explored cancer patients' reflections about good nursing care by using the general resistance resources (GRR) theoretical framework originally developed by Antonovsky. The results of their study indicated that receiving good care from health care professionals can be an important resource for patients by activating their GRRs in stressful situations, such as when they receive a diagnosis of cancer. Kvåle and Synnes found that the majority of patients in their study succeeded in activating their GRRs and were able to deal more efficaciously with stressors and subsequently had better care experiences. They also found that similar to supportive family members and reliable friendships, good health care helps to alleviate physical suffering by promoting a sense of coherence.

Hoffman, Lent, and Raque-Bogdan (2013) described the social cognitive model as the framework for coping with early-stage cancer. Hoffman et al. examined the ways in which self-efficacy, beliefs, environmental supports (physical care and psychosocial care), and cancer-related coping strategies improved the survival rates of newly diagnosed cancer patients. Hoffman et al. also highlighted the important psychosocial requirements and support systems needed by cancer patients.

Zettervall (2014) used an extension of the mathematical fuzzy set theory in cancer care. Zettervall used the theory as the basis for predicting a prognosis of gastric cancer and the choice of treatment modality for prostatic carcinoma. Zettervall predicted that prognoses will determine the usefulness of surgical interventions in treatment plans for gastric cancers.

Duggleby et al. (2010) described the transitions experienced by older persons living in rural areas who were receiving palliative home care and their family members. Using Charmaz's (2006) CGT, they conducted in-depth interviews with six elderly patients with advanced cancer and 10 bereaved family caregivers, as well as four focus group sessions with 12 palliative care physicians. They found that because of rural isolation, limited accessibility to services, and lack of information, these patients and their families experienced multiple challenging transitions in physical and mental health, relationships, and activities of daily living that resulted in uncertainty and distress. Duggleby et al. subsequently developed the substantive theory of transitions, which emphasizes the need for good communication between cancer patients living in rural areas and their health care providers.

Ledford et al. (2010) studied the perceptions of patients regarding the competence and expertise of their physicians. The study was based upon the classic grounded theory approach, and Ledford et al. developed a theory about the connections between patients' adherence to treatment plans and their perceptions of the trustworthiness and competence of their health care providers. The health care providers' practice of changing and shuffling medication without adequate explanation or justification gave the patients reason to perceive them as untrustworthy and incompetent.

### **Theoretical Foundation**

Current theories do not adequately explain the perceptions of cancer survivors about their care in Nigeria. I saw a need to develop a local theory that was appropriate to Nigerian culture and experience. The CGT approach allowed me to understand the meanings of their experiences and generate a theoretical model based upon those experiences (Charmaz, 2006; Clarke, 2005).

Glaser and Strauss (2009) suggested a research methodology in 1967 that systematically derives human behavioral theories from empirical data that they termed *grounded theory*. The basis for the development of this theory resided in Glaser and Strauss's rejection of the approach of simply testing preexisting theories instead of constructing new theories through data analysis (Charmaz, 2014; Glaser & Strauss, 2009). They developed a theory from empirical data, that is, without preconceived theoretical ideas prior to the data analysis. It was based upon a method involving constant and continuous comparisons of collected data with preexisting constructs and concepts. I chose the CGT approach to explore the perceptions of cancer survivors in Nigeria about

the care that they received from health care providers by analyzing data collected from the cancer survivors themselves. The CGT approach allowed me to develop a theory based upon the data derived solely from the participants.

### **Conceptual Framework**

After reviewing the literature, I decided that the conceptual framework of the study would be the PCC model, which uses the most current best evidence in the care of individual patients according to their own contexts (Weiner et al., 2013). This context includes all factors that are relevant to their care, including life circumstances and behaviors (Weiner et al., 2013). This framework has been used in clinical research to study different aspects of patients' satisfaction with the health care process and outcomes. The core components of PCC are patients' awareness of their conditions, treatment options available to them, feelings of respect and dignity in clinical encounters, and facilitation of involvement in the decision-making process (Epstein & Street, 2011a; see Figure 1).

The PCC theoretical model is based upon the quality of communication between health care practitioners and patients (Hudson, Fortin, Haggerty, Lambert, & Poitras, 2011; Linden, Vodermaier, MacKenzie, & Greig, 2012). It has been used specifically to determine the role of physicians in cancer care delivery by focusing on the barriers to effective cancer care and determining how cancer patients perceive their treatment outcomes (Balogh et al., 2011; Tsianakas, Maben, et al., 2012). This framework guided the current study on the ways in which cancer patients in Nigeria perceived the care delivered to them by health care professionals.

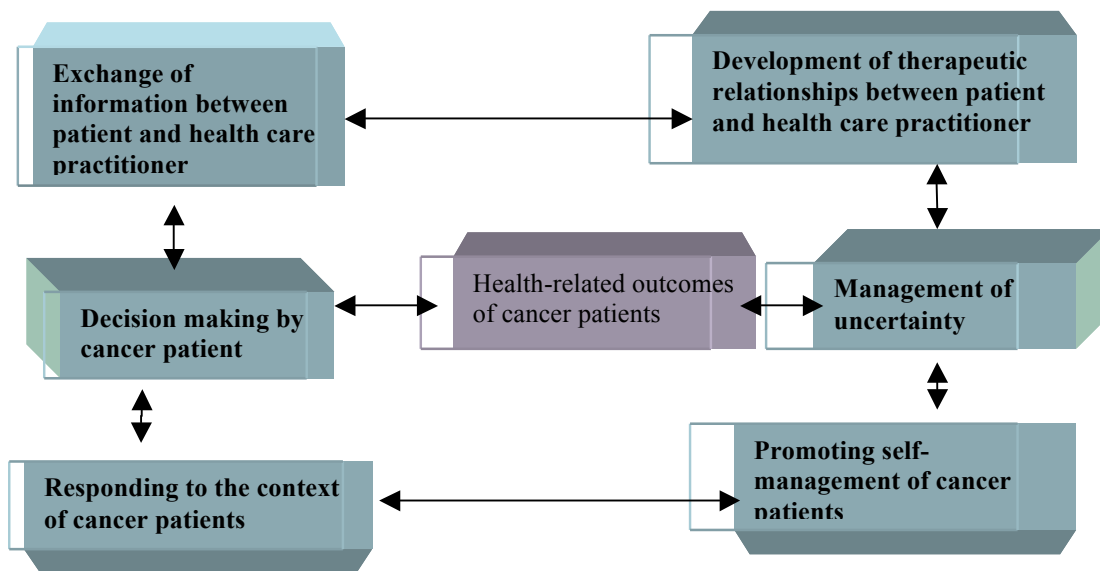


Figure 1. A flowchart showing the PCC model.

### Review of the Literature

Researchers have studied the importance of the perceptions of cancer patients about various aspects of their care. These perceptions have been shaped by the quality of care received from health care professionals and the sociodemographic characteristics of the patients. Several studies on cancer patients' perceptions of their care have been conducted across the globe, but my review of the literature identified significant gaps in the research about cancer care. These gaps motivated me to conduct this qualitative study to explore the perceptions of cancer survivors in Nigeria about the care delivered to them by health care providers.

### What Do Cancer Patients and Providers Consider Quality Cancer Care?

In the United States, health care providers have focused greater attention on quality and value and what they mean to health care consumers (Kennedy, Caselli, & Berry, 2011). Under the Value-Based Purchasing (VBP) Program, reimbursement for



inpatient Medicare services is determined by clinical outcome and service quality parameters (Kennedy et al., 2011). Kennedy et al.'s (2011) survey on health care service user in the United States showed that service users considered care to be of high quality if it was delivered by health care professionals who were thorough, spent enough time listening to their complaints, used words and terms easily understood by the patients, involved patients in decisions, and were courteous and caring while explaining the patients' medical conditions.

There has been an evolution in the ways in which breast cancer has been diagnosed and managed since 1980, such as how multidisciplinary specialties at comprehensive breast centers care for cancer patients. The development of magnetic resonance imaging (MRI) has revolutionized the diagnosis of breast cancer and has made targeted therapy in the adjuvant setting possible. Most centers now perform breast-conserving surgeries, much to the relief of cancer patients who have been uncomfortable with the idea of radical mastectomies and their physical and emotional complications. Cancer patients consider timely access to care by MDTs an important indicator of efficient care (Kiely, 2014). This belief explains why the National Consortium of Breast Centers, the American College of Surgeons, and the IOM recommended timely care by MDTs of competent and compassionate nurses and physicians as one way to achieve high-quality cancer care (Kiely, 2014).

Fessele, Yendo, and Mallory (2014) used 39 sites to test breast cancer care (BCC) measures focusing on different aspects of care: the accurate assessment and documented treatment of symptoms such as nausea, vomiting, sleep disturbances, anxiety, depression,

and lymphedema among patients with advanced cancer who were receiving chemotherapy. Because randomized clinical trials and meta-analyses have confirmed exercise as an effective intervention for fatigue, depression, anxiety, lymphedema, drowsiness, and insomnia in cancer patients receiving chemotherapy, Fessele et al. also examined the percentage of patients to whom exercise was recommended before they received chemotherapy.

The BCC scale measures how consistent health care professionals are in educating patients and family members about hand hygiene and the specific temperature that should alert them to the need to call the oncology practice for those at risk of febrile neutropenia. The final measure evaluates whether the appropriate treatments have been prescribed to patients with dangerously low white cell counts while undergoing chemotherapy (Fessele et al., 2014). Results of the study showed a significant gap in care to be addressed.

Cancer survivors need follow-up after their initial treatment to ensure that any recurrences of the cancer or any late side effects are identified early and treated appropriately. Weaver et al. (2014) e-mailed questionnaires to long-term cancer survivors (i.e., 4 to 14 years after diagnosis) randomly selected from the California Cancer Registry. They found that the respondents considered their follow-up care years after initial diagnosis and discharge back to the communities important. The survey also found deficiencies in the follow-up care provided for these cancer survivors. The cancer survivors rated the care provided by MDTs led by specialist oncology physicians as high

quality. They also rated care from the same health care professionals over a long period as high quality (Weaver et al., 2014).

The increasingly complex nature of cancer care and the involvement of MDTs in the acute care, home, and community settings have resulted in increased risk of care discontinuity, reduced access to care, poor care coordination, and inadequate responses by health care professionals to patients' overall care needs. Saunders, Abel, and Lyrtzopoulos (2015), who used anonymous data from a survey of cancer patients treated in NHS hospitals in England, found that appreciating how care experiences varied among patients with different sociodemographic characteristics and different cancers is an important first step in helping to understand response mechanisms and the development of targeted interventions for improvement.

Deficiencies in the quality of care and the subsequent need for improvement have been recognized in many industrialized countries, including the United States, Australia, England, and France (Brédart et al., 2015). Patients' perceptions of their care were found to be important indicators of the quality of care, complementing the findings from more objective quantitative studies on the technical aspects of care, such as new medications and other forms of therapies. Brédart et al.'s (2015) assessment of patient satisfaction provided information on the link between how a service is meeting patients' needs and expectations.

Patients who are satisfied with their care are more likely to comply with treatment schedules in maintenance therapies. Satisfaction with cancer care has been associated with improved compliance with treatment schedules and improved clinical outcomes.

Gerties et al. (as cited in Brédart et al., 2015) identified six dimensions of PCC: respect for patients' values, preferences, and expressed needs; emotional support; physical comfort; information and education; coordination and integration; and attention to family and friends. Evaluation of the extent to which these dimensions of care have been met requires patient input (Brédart et al., 2015).

The care of cancer patients has increasingly moved to the home setting, where family members have assumed responsibility for providing physical care, medication administration, and symptom monitoring without any supervision from trained nurses. According to Douglas and Daly (2014), it is important to attend to family needs as an integral part of quality cancer care. All of these needs increase as the EOL approaches. Five domains of EOL care define QoL: physical well-being, patient autonomy, assistance to family members as advocates for cancer patients, education of family members to instill confidence in their new roles, and emotional support to family members. These needs of family caregivers include psychosocial support, education, and practical help in providing care to cancer patients.

### **Impact of Cancer on Patients' Quality of Life**

Cancer patients experience various physical and psychological outcomes resulting from their experiences during diagnosis and treatment. These outcomes can have a considerable impact on their QoL. Linden et al. (2012) conducted a survey to study the incidence of depression and anxiety among cancer patients following diagnosis and identify variations in their levels of depression and anxiety with age and gender. The study was based upon a cancer survey at two cancer centers between 2004 and 2009. This

method was selected because the data were gathered through the screening of cancer patients for psychological outcomes. Anxiety was reported by 19% of the participants; 12.9% reported clinical levels of depression. Significant differences in the incidence of depression and anxiety were related to gender and type or stage of the cancer. Depression and anxiety levels were significantly high among the female participants who had been diagnosed with advanced cancer.

Thapa, Rawal, and Bista (2010) also used a questionnaire to gain information about the incidence of anxiety and depression among the cancer patients. They took a more systematic approach and used a case control design to differentiate between the levels of these psychological outcomes in healthy individuals and cancer patients.

Anxiety was observed in 40% of the patients, and depression was detected in 28%.

Cramarossa et al. (2013) conducted a similar study and found that pain, adverse emotional functioning, and loss of appetite affected the overall QoL of the cancer patients.

Brakel, Dijkstra, and Buunk (2014) noted that the QoL of cancer patients who are in the recovery phase is under constant pressure. Health care professionals who are looking after cancer patients are responsible for listening to patient reports of symptoms; adverse reactions; mild, moderate, and severe side effects of treatments; and any QoL changes that are unique to them but previously unknown to the carers in order not to miss anything (Underhill, Sheldon, Halpenny, & Berry, 2014). Health care professionals must approach QoL changes as a routine part of multidisciplinary clinical care considerations. There should be communication protocols in MDTs to gather information about QoL concerns and ways to manage them. MDTs should be able to intervene to maximize the

efficacy and safety of therapy to improve treatment outcomes for cancer patients (Underhill et al., 2014).

In India, according to Shakeri et al. (2015), diagnosis of a malignant, life-threatening cancer is a life-changing development. Cancer and its treatment might lead to real physical disfigurement of patients that can negatively impact the QoL in terms of self-confidence, self-esteem, social interest, social withdrawal, and stigma. Therefore, it is imperative to manage these QoL problems adequately by providing social and psychological support to cancer patients and the family members directly involved in their daily care.

Gynecological and urological cancers that have an impact on sexual health of patients also can impact their QoL. Cancer and its treatment can impact the mental and social health of patients and their families as well. In a unique study, Zahlis and Lewis (as cited in Shakeri et al., 2015) asserted that a diagnosis of breast cancer affects not only the women but also their male spouses, resulting in considerable changes to their QoL. According to Duggleby et al. (2015), the male spouses of women with breast cancer also experience significant levels of mental health symptoms such as disruptions in their sleep-wakefulness cycle, appetite for food, and ability to keep their jobs because of their impaired ability to concentration and their increased anxiety levels.

Patients' mental health and QoL issues should be part of the deliberations of caring MDTs because the indicators of treatment outcomes for cancer patients have been expanded to include QoL along with survival rates. In China, both Xu and Wang as well as Wang et al. (as cited in Ma, Wa, & Wang, 2014) found that QoL can more accurately

reflect treatment outcomes than the survival and mortality rates in the patients with cancer can. Lavdanti and Tsitsis (2015) asserted that cancer and the toxicity of treatment can impact the ability of patients to fulfil familial and societal roles, such as being gainfully employed or participating in common social responsibilities. Despite the early detection of cancer and the new treatments that offer better prognoses, cancer remains a chronic illness. Together with the treatment protocols, cancer continues to affect the QoL of patients (Lavdanti & Tsitsis, 2015).

Sekse, Hufthammer, and Vikan (2015) noted that cancer-related fatigue is among the most frequently reported side effects of cancer and its treatment modalities. Fatigue is common across all types and stages of cancer. Unexplained fatigue commonly suggests to health care professionals the possibility of undetected cancer and usually leads to physical examinations and laboratory tests. A diagnosis of cancer can be confirmed after histological and radiological examinations. Cancer patients often describe fatigue to health care professionals as a feeling of tiredness or exhaustion, and some cancer patients continue to experience cancer-related fatigue long after treatment. Fatigue affects the QoL as cancer patients, who tire too quickly to return to previous familial, societal, and work-related activities.

### **Coordination and Continuity in Cancer Care**

Patients with chronic illnesses such as cancer receive treatment in the acute care hospital setting and continue to receive care after they return to the community (Walsh et al., 2011). Transitions in care from cancer specialists in the acute care hospital setting to primary care practitioners in the community setting leave room for improvement because

community practitioners might be lacking the confidence and skills necessary to care for cancer survivors in the primary health care setting (Nekhlyudov, 2014; Walsh et al., 2011). The care of cancer patients requires the involvement of health care practitioners in acute and primary care settings (Nekhlyudov, 2014). As cancer patients progress through different phases of care, primary care practitioners need adequate training to prepare to care for cancer patients after discharge from hospital (Nekhlyudov, 2014). The introduction of MDTs into the care of cancer patients has reduced the unnecessary duplication of tests, the number of inappropriate or incorrect actions resulting from incomplete information, inefficient care, poor health outcomes, and health care costs.

### **Role of Health Care Practitioners in the Care of Cancer Patients**

Studies have been conducted to examine the role of health care practitioners in cancer care by exploring the perceptions of the practitioners themselves. In a qualitative study based upon in-depth interviews with doctors to gain their perceptions of their role in cancer care in the Netherlands, Geelen, Krumeich, Schellevis, and van den Akker (2014) found that the doctors believed that they needed to provide more information to their cancer patients. Johansen, Holtedahl, and Rudebeck (2010) conducted a similar study in Norway. They used semistructured interviews of a sample of general practitioners to explore their role in cancer care. The results showed that the doctors played an intermediary role between patients and practitioners at tertiary health care centers during the diagnosis and treatment of cancer. The methodology used in both studies was appropriate to deal with the emotionally evocative nature of the research



topic. However, these results were limited only to situations in the Netherlands, Austria, and Norway.

The experience of nurse practitioners (NPs) in the care of cancer patients also has been explored in qualitative studies. Watts et al. (2010) conducted a qualitative study to identify the NPs' perceptions of their role in the care of cancer patients. They used focus groups because of the exploratory nature of the RQs. Results indicated that the NPs experienced several negative aspects of cancer care, namely, frustration, anger, and inadequacy of communication with health care practitioners. This study explored the perceptions of NPs within a clinical setting (Watts et al., 2010).

Suija, Ilves, Ööpik, Maaros, and Kalda (2013) conducted a qualitative study using semistructured interviews to obtain cancer patients' perceptions of the role of oncologists and primary care practitioners in cancer treatment. The participants considered the role of oncologists in their treatment to be more important than that of the primary care practitioners (Suija et al., 2013). The findings of the study are vital in supporting improvements in the role of primary care practitioners in cancer care.

Sorkin, Ngo-Metzger, and De Alba (2010) conducted a cross-sectional study of the correlation between perceived discrimination and perceptions of quality of care, regardless of differences in patients' access to care and sociodemographic characteristics. They found that perceptions of discrimination by the cancer patients led to poor adherence to medication regimens, cancer screening recommendations, and health-related advice from health care professionals.

## **Communication in Cancer Care**

Clear and open communication is valued in cancer care because it determines the extent of information exchanged between health care practitioners and cancer patients (Hoerger et al., 2013). Stajduhar et al. (2010) conducted a qualitative study using in-depth interviews and focus groups to explore cancer patients' perceptions of the quality of communication with their health care providers. Stajduhar et al. found that the cancer patients preferred their health care professionals to communicate clearly and honestly with them to give them hope and to be respectful, caring, and empathetic. The use of interviews and focus groups allowed Stajduhar et al. to gain insight into the needs of cancer patients, whose perceptions should be the real indicators of their needs. The observations made in this study by Stajduhar et al. were important to the development of evidence-based cancer care practice.

A similar study was conducted by Wang et al. (2013), who analyzed cancer patients' perceptions of the significance of effective communication. They conducted a qualitative study using focus groups and interviews to obtain the perceptions of breast cancer patients about their communication experiences during diagnosis, treatment, and follow-up with physicians. The cancer patients considered the provision of adequate information related to various stages of their cancer care by physicians the most important aspect of their care. The sample comprised only breast cancer patients, which limited its applicability to patients with other types of cancer (Wang et al., 2013).

Interviews and focus groups also were used by McLean, Cleland, Worrell, and Vögele (2011) to explore the perspectives of nurses and physicians on communication

needs and experiences with cancer patients. Emotional containment during communication with cancer patients was considered important, along with the delivery of appropriate information, support, and the provision of sufficient time (McLean et al., 2011). The strength of this study was its relevance to clinical practice. However, because the study was conducted in only one setting in the United Kingdom, the results might not be generalizable to all cancer patients (McLean et al., 2011).

The goal of the IOM's conceptual framework to improve the quality of cancer care was to ensure that cancer care is accessible, comprehensible, patient centered, evidence based, and high quality (as cited in Nekhlyudov et al., 2014). The national cancer policy recommendation is that health care providers charged with caring for cancer patients should engage meaningfully with patients and their families to develop evidence-based treatment plans while also respecting the emotional, social, and cultural needs and aspirations of cancer patients and their families (as cited in Nekhlyudov et al., 2014). This recommendation will help cancer health care professionals to personalize treatment recommendations, use understandable language, provide clear explanations, and address patients' emotional states (Epstein & Street, 2011b; Hoerger et al., 2013).

### **Cancer Patients' Perceptions of Health Care Providers**

Cancer patients have various perceptions of the nurses who are involved in various aspects of their psychological and physical care. The Flemish Care-Q instrument has been used to obtain the perceptions of cancer patients about the importance of nurses in their care (Van der Elst, de Casterlé, Biets, Rchaidia, & Gastmans, 2013). The patients described better nurses as being supportive, communicating better, and demonstrating

professional attitudes and attachment toward patients and family members (Van der Elst et al., 2013).

Larsson, Sahlsten, Segesten, and Plos (2011) explored cancer patients' perceptions of the effect of nurses' behavior on their care. Involving patients in their own care through the delivery of appropriate information by nurses and recognizing patients as competent individuals motivated them to participate in their own care (Larsson et al., 2011). Lack of clear information was identified as the major factor for the nonparticipation of cancer patients in their care (Larsson et al., 2011). Although the demographics of the participants were diverse in term of ethnic background, gender, and age, all of them were patients of a single clinic, so the findings might not be applicable in a wider context (Larsson et al., 2011)

### **Patients' Perceptions of Effective Cancer Treatment**

For the treatment of cancer to be effective, many aspects of care must be addressed by health care providers. Peppercorn et al. (2011) studied three significant aspects of cancer care: symptom management, disease-directed therapy, and attention to QoL. They concluded that cancer patients face difficult psychological, physical, and social consequences resulting from cancer and its treatment. Peppercorn et al. also found that patient care must encompass patients' individualized assessment preferences, goals, and needs throughout the course of the illness.

A mixed methods study was conducted by Tsianakas, Robert, et al. (2012) on the views of cancer patients regarding ways to improve the quality of care being delivered by health care practitioners. Using a questionnaire and in-depth interviews, Tsianakas,

Robert, et al. found that the patients in their study considered the provision of information and their engagement in the treatment process as important features of effective care. Use of a mixed methods study allowed the researchers to gain deeper insight into the perspectives of the cancer patients.

Horvath et al. (2010) as well as Litton et al. (2010) examined MDT cancer care with a focus on physician and patient satisfaction. Both teams of researchers found that improving communication, increasing efficiency, and building patient confidence led to improvements in patient care. They also found that cancer patients preferred care delivered by MDTs to decrease the fragmentation of care and reduce the number of clinical errors, the duplication of tests, and differences in clinical opinions among health care professionals (Horvath et al., 2010; Litton et al., 2010). In addition, MDT care ensures better communication and clearer treatment plans, improved QoL, good clinical practice, and increased enrollment in treatment programs (Horvath et al., 2010; Litton et al., 2010).

Hawley et al. (2010) studied the effect of health literacy on the perceptions of cancer care by women with breast cancer. Hawley et al. found that low health literacy levels were associated with poor perceptions of the coordination of care services. However, they found no correlations between service coordination and ethnicity.

### **Strategies to Improve Cancer Care**

There is considerable variation in cancer patients' perceptions of good care because how patients perceive health care is determined by such factors as value systems, self-reported health status, the use of complementary and alternative medicine, and

reasonable wait times for care from health care professionals (Kallen, Terrel, Lewis-Patterson, & Hwang, 2012; Nguyen et al., 2014; Tsianakas, Maben, et al., 2012).

Tsianakas, Maben, et al. (2012) reported that improving wait times for care, giving written information to patients, and paying attention to patients' concerns will improve their perceptions of their care.

In a study on the effects of patients' preconceptions, perceptions, and knowledge about cancer on the uptake of cancer care in Pakistan, Kumar, Shaikh, Khalid, and Masood (2010) found that most of the cancer patients in their study believed that cancer could be prevented or cured through the avoidance of such harmful habits as alcohol and tobacco misuse and more engagement in religion. Kumar et al. posited that patients want their physicians to involve them and their families in all major decisions concerning their care. These findings are important now because people from different ethnic and cultural backgrounds are living in parts of the world that might not be familiar with their perceptions and knowledge of cancer care (Kumar et al., 2010).

Otani, Herrmann, and Kurz (2011) reported that empathetic health care professionals can enhance cancer patients' perceptions of their care. This assertion was confirmed by Charalambous and Kaite (2013), who conducted a hermeneutic study on undergraduate nursing students caring for cancer patients. They found that being sympathetic, self-reflective, and caring toward the patients and their family members, as well as improving their own clinical skills, significantly improved the care of cancer patients and patients' perceptions of their care. Gagliardi et al. (2014) found that the implementation of diagnostic assessment programs can improve the interprofessional

collaborative care (ICC) of cancer patients. Improved ICC is beneficial to patients, the health care system, and health care professionals (Gagliardi et al., 2014)

### **Summary and Conclusions**

In this chapter, I discussed the strategy to search for the most appropriate literature related to the care of cancer patients by health care practitioners and their perceptions of this care. I searched a variety of electronic databases through Google Scholar to retrieve full-text articles from peer-reviewed journals published mainly between 2007 and 2015. I conducted this qualitative study using the CGT approach, which facilitated the development of a new theory through the process of constant comparison of the qualitative data collected through interviews and focus groups. This process allowed me to explore the perspectives of cancer patients in Nigeria about the health care that they received from health care providers while undergoing treatment.

The conceptual framework of the study was PCC (Tsianakas, Robert, et al., 2012). No significant study has been conducted to obtain the perceptions of cancer patients regarding the ways in which care their care was delivered by their health care practitioners. This study might help the stakeholders to understand the requirements and expectations of cancer patients so that health care practitioners can incorporate the necessary changes into their practice.

Despite the rigor of the aforementioned studies, the researchers were unable to answer questions concerning the perceptions of cancer patients about the care received from health care professionals. I suggest that only a study based upon a qualitative design could best answer those questions. The strength of these previous studies resided in their

capacity to deal with extensive quantifiable data; their weakness was their incapacity to observe the descriptive contexts of the perceptions of cancer survivors.



## Chapter 3: Methodology

### **Introduction**

The purpose of this study was to develop a theory based upon the perceptions of cancer patients in Nigeria about the care delivered to them by their health care practitioners. The study was specifically designed to collect information that will help cancer care practitioners to plan initiatives to enhance the experiences of cancer patients during treatment and to provide efficient and satisfactory care to cancer patients and their families. I collected empirical data from in-depth interviews and theoretical group interviews with a sample of cancer survivors who had received treatment and had then returned to their communities. The study design emphasized the importance of understanding the perspectives of cancer patients so that practitioners might then reflect on the quality of physical, social, psychological, cultural, spiritual, and emotional care that they provide from diagnosis to the end stage of cancer, as suggested by Smith, Wai, Alexander, and Singh-Carlson (2011). The results also might help patients to develop more positive perceptions of their health care professionals and the care that they deliver (Rehnberg, Absetz, & Aro, 2001).

In this chapter, I discuss the CGT, which is a qualitative design, and the rationale for its selection. I explain my role as the researcher, including my relationship with the participants, bias management, and the ways in which I dealt with ethical issues. I provide an in-depth explanation of the rationale for the selection of the participants and the data collection instruments. I also include information about the recruitment of the

participants and the data collection process, and I explain the data analysis plan and various issues related to the trustworthiness of the study.

### **Research Design and Rationale**

The study was based upon a qualitative design that I used to obtain the perceptions of cancer survivors in Nigeria about the care that they received from their health care professionals during treatment. This design allowed me to obtain the perceptions of the cancer survivors and the factors influencing these perceptions.

### **Research Question**

I conducted this study to generate a theory based upon the data collected from the participants (Creswell, 2009). The study was guided by one overarching RQ: What are the perceptions of cancer survivors in Nigeria about the care delivered by their health care practitioners? This central question led to the generation of subquestions that had direct implications for the data generation and analysis procedures (Creswell, 2009; Rudestam & Newton, 2007).

### **Subquestions**

1. How do major indices of survivor' perceived quality of cancer care indicate positive or negative perceptions toward the care?
2. What do cancer survivors perceive as the desired goal of their care?
3. How do cancer survivors perceive the way through which the desired goal of their care is achieved?
4. What factors contribute to the different levels of survivors' perceptions about the care received from health care providers?

5. How can survivors' perceptions about the care received from health care providers be improved?

Matching the emergent theory or hypothesis or model with professional practice and the factors that contributed to the cancer survivors' perceptions of their care, along with the manner in which they could have been altered, were addressed through this research design.

### **Central Phenomenon of the Study**

In this study, I collected the perceptions of cancer survivors in Nigeria about the care provided by their health care practitioners during treatment. Cancer patients consider the competence of health care providers important to ensure the adequate and appropriate delivery of care to treat and manage their disease (Weaver et al., 2014). Cancer patients also value the humanistic aspects of care, and they consider oncology nurses and other health care professionals competent individuals who have the skills and knowledge essential to provide high-quality care (Kvåle & Bondevik, 2010). It was essential to explore the perceptions of cancer survivors because the literature has identified several factors that can affect these perceptions (Lee, Kilbreath, Sullivan, Refshauge, & Beith, 2010).

### **Research Tradition and Rationale for Its Selection**

The social change implications of the study could be appreciated only after reaching a clear understanding of the research paradigm (Hall et al., 2013). This study was inductive, and the approach was the CGT. The ontology was relativist, with transactional and subjectivist epistemological relationships between myself and the

participants, as suggested by Hall et al (2013) and Johnson (2014). I used this inductive study to develop a new theory through the active processes of interpretation and comparison of the empirical data collected from the participants, as suggested by Hall et al (2013) and Johnson (2014). I analyzed the collected data to generate a new theoretical account grounded in the data obtained from the in-depth interviews and the theoretical group interviews, along with field notes that I recorded in a journal during the interviews, as suggested by Green and Thorogood (2009), Hall et al. (2013), and Johnson (2014)

In grounded theory, data collection and data analysis are interwoven. This process follows a continuum of reciprocal exchanges between data collection and data analysis; it has been described as constant comparison and theoretical sampling (Hall et al., 2013; Johnson, 2014). The first step is open coding, which involves a thorough review of the raw data. I checked the transcriptions of the interview responses to identify codes that would change as their characteristics were reviewed and the analysis progressed. The next step is selective, or focused, coding, which puts the different segments identified by the open coding together again by looking at the relationships between and among these different segments. The final phase of the coding process is theoretical coding, which generates the core categories, that is, the categories with the most explanative powers (Hall et al., 2013; Johnson, 2014). During this stage of the data analysis, the content of the memos written during the analysis is incorporated into the data analysis process, as suggested by Hall et al. (2013) and Johnson (2014).

### **Role of the Researcher**

I had a subjective and an interactive relationship with the participants. The data collection protocol was based upon instruments that had the potential to be influenced by my attitudes and other idiosyncrasies. My role in selecting the participants, data collection instruments, and data analysis impacted the results of the research. Because I was not free of researcher biases and had my own perspectives, these also had the potential to impact the outcomes of the study.

According to Creswell (2007, 2009), qualitative research is interpretative; in this study, I was involved in intensive experience with the participants during the individual interviews and the theoretical group interviews. I am a health care provider with 27 years of experience in dealing with patients with cancer and other serious health issues. I had to separate the professional experience of looking after patients from the data collection processes of this study to avoid collecting biased or compromised data from the participants, as suggested by Creswell (2009).

I went through the process of obtaining permission from Walden University's Institutional Review Board (IRB) and from the board of trustees of an NGO to recruit their service users as participants for this study. I anonymized the names of the participants, the NGO involved in the study, and the location of the NGO to protect the privacy of the participants. I also developed a good relationship with the participants that made them feel comfortable enough to share private information, as suggested by O'Leary (2004) as well as Rudestam and Newton (2007).

### **Personal and Professional Relationships With Participants**

I played an essential role in the collection and analysis of data to ensure that the results were based upon valid and reliable interpretations. I established good rapport with the participants before and during the individual and theoretical group interviews. The relationship with the participants was not connected to my professional status as a doctor because it was meant to keep the participants at ease and allow them to discuss problems that were personal to them with me, a complete stranger to them. Although I was introduced to the participants as a health care practitioner, the relationship that developed was very informal in order not to influence the outcomes of the study. As suggested by Robertson and Hale (2011), I did not direct the conversations during the interviews.

### **Management of Researcher Biases and Power Relationships**

I endeavored to avoid researcher bias during the data collection and analysis processes. I managed researcher bias and power relationships by self-evaluating my role as the researcher when I developed the RQ and subquestions, as suggested by O'Leary (2004). The study involved interactions with cancer survivors, individuals who might have been vulnerable; therefore, I did not induce, encourage, or coerce any participants into providing information that they were not comfortable disclosing as suggested by Green and Thorogood (2009). Only issues relevant to the research topic were discussed during the interviews. I ensured that my personal opinions and emotions did not influence the participants' responses, as suggested by Green and Thorogood (2009) and O'Leary (2004).

## **Methodology**

I chose to conduct qualitative research to develop an in-depth understanding of the perceptions of cancer survivors about the care delivered to them by health care providers during treatment. The focus of qualitative research is to study people and places in their natural settings and to answer questions regarding the what, why, and how of the phenomena under investigation (Green & Thorogood, 2009). The research paradigm is subjectism, interpretism, or constructivism (Creswell, 2007). It does not involve the manipulation of variables and the use of statistics to answer any RQs (Creswell, 2009). Qualitative research facilitates the analysis and interpretation of data that cannot be presented in numerical form. It emphasizes the description and elucidation of data that can lead to the development of new notions and theories that can be tested using different methodologies (Creswell, 2009; Hancock, Ockleford, & Windridge, 2009). I followed the CGT approach described by Charmaz (2006). The rationale for this choice of methodology was that as a health care practitioner involved in the care of cancer patients, I could not credibly claim to be neutral because I intended to bring my experience as a health care professional into this study.

### **Participant Selection**

The target population comprised people in Nigeria who were cancer survivors. Because the CGT allows researchers to use purposive sampling to obtain their participants, I selected the participants based upon specific criteria that facilitated the collection of relevant information related to the RQ and subquestions, as recommended by Oppong (2013). The participants belonged to various ethnic and racial groups in

Nigeria and had diverse characteristics in terms of age, religious beliefs, gender, SES, level of education, and immigration status. The study began with a pilot study using six participants for the initial data collection; these participants were cancer survivors who had resumed their former roles as people free from cancer after receiving treatment. Because the data collection and analysis protocols occurred simultaneously, I recruited more participants over the course of the study, as suggested by Creswell (2009). I had 30 participants by the end of the data collection and analysis stages. I interviewed all 30 participants individually and also recalled the participants in five small groups of six participants each for theoretical group interviews in order to modify and saturate the emerging theoretical model, as recommended by Creswell (2007, 2009); Morse (2007); and Sargeant (2012).

The chair of a cancer support NGO in Nigeria introduced me to the cancer survivors as potential participants. Only cancer survivors who self-identified as physically and emotionally fit were recruited for the study. The preliminary step was to e-mail an introductory letter about the study that also outlined their rights as participants. I recruited the participants following this self-identification and the signing of the consent form. Data saturation occurred when no further information emerged from the individual interview responses or the theoretical group interviews (Suter, 2011).

### **Instrumentation**

I conducted 30 semistructured interviews and recalled these participants in five small groups of six for theoretical group interviews guided by the interview protocols approved by Walden University's IRB and based upon the RQ and subquestions.



Interviewing is the best available method to collect data from a sample from a particular target population (Creswell, 2007, 2009; Green & Thorogood, 2009). Each face-to-face interview was about 45 minutes, and each theoretical group interview session was 1 hour, sufficient times to collect enough data to answer the RQ and subquestions in the individual interviews and enough time to expand verify, modify, and saturate the emerging model during the theoretical group interviews. I gave the participants ample time to provide responses or share in discussions (Green & Thorogood, 2009).

I audiorecorded the interviews in order to analyze and then interpreted the participants' responses (Jacob & Furgerson, 2012). I also conducted the interviews in locations that ensured the privacy of the participants and maintained the confidentiality of their responses. In addition, I provided additional information about the study to the participants.

I followed Walden University's approved interview protocol and asked eight open-ended questions to gather additional information about the experiences and perceptions of the participants. Open-ended questions are important in exploring the views, beliefs, attitudes, and opinions of study participants without limiting the scope of the expected responses (Green & Thorogood, 2009; Hesse-Biber & Leavy, 2010). I asked more probing questions only later in the interviews to give the participants time to develop their trust in me before sharing more information. These participants discussed their experiences and perceptions of their care while undergoing treatment for cancer. The participants shared their thoughts and opinions about their different care experiences (Liamputtong, 2011). I took field notes and wrote memos to document all aspects of the

participants' behavior and body language so that the cultural and behavioral context of the research could remain intact.

### **Recruitment, Participation, and Data Collection**

The process of recruiting participants was carried out through a cancer support NGO, whose chair gave me written permission to contact its service users who were cancer survivors. He introduced me to cancer survivors who meet the inclusion criteria for this study. I purposefully selected the initial six participants from these cancer survivors. I informed these individuals about the research and the extent of their participation to ensure that they understood the consent protocol. Information about their rights as participants, including the right to withdraw from the study at any time without repercussions, was provided to them in writing.

I coded and analyzed the initial data collected from these six participants. The theoretical concept emerging from this analysis directed the recruitment of 30 participants in total using theoretical sampling, until data saturation occurred, as recommended by Creswell (2009) and Rudestam and Newton (2007). This theoretical sampling technique allowed me to collect and analyze the data simultaneously by looking at the themes that emerged in the previously analyzed data with the themes guiding the recruitment of other participants, as suggested by Creswell (2007) as well as Rudestam and Newton (2007).

The data underwent three levels of coding, that is, open; selective, or focused; and theoretical coding, during the analysis. As mentioned earlier, selective coding generates categories with the most explanative powers. The process of theoretical sampling, which

was based upon these core categories, continued until data saturation was reached, as suggested by Creswell (2009).

At the beginning of each interview session, I reviewed the consent form again with the participants to confirm their understanding of it and to give them the opportunity to ask me questions about the study. Although it is not a requirement in qualitative studies in general, grounded theory in particular, I collected demographic information from the participants. The interviews began with open-ended questions, with the participants free to discuss what they perceived as issues importance to their experiences while receiving care for cancer. These questions were followed by more specific questions. At the end of each interview, I briefed the participants about the possible need to contact them for follow-up interviews if I required additional information. I thanked them for their participation and assured them that I would maintain the confidentiality of the information that they shared with me.

### **Memoing and Field Notes**

The writing of memos during CGT studies is essential and continues throughout the different phases of such investigations. I used memos to be self-reflexive and to link the data collection to the data analysis. Memos helped me to keep my assumptions in check, identify possible biases, and allow me to reflect on my interpretations to gain a deeper understanding of the participants' perceptions and experiences. The memos helped me to clarify categories while transforming descriptive data into concepts and theories as suggested by Charmaz (2014) and Urquhart (2013). I will keep the memos securely stored in a password-protected laptop computer, and I will destroy all

documentation, electronic or otherwise, upon completion of the study and dissemination of the findings. None of the stored documents contains any traceable personal information on any of the participants, as suggested by Charmaz (2014) and Urquhart (2013).

### **Data Analysis Plan**

The study was based upon the CGT approach, first described by Charmaz (2014), a student of Strauss and Glaser, originators of the grounded theory method (Urquhart, 2013). This approach involves a cyclical process of data collection, coding, categorization and theoretical sampling, theoretical sensitivity, constant comparative analysis, and writing of memoranda and diagramming, and back again to the open initial coding, constant comparative analysis, categorization, and writing of memoranda to abstract a theory that responds to the RQ, as suggested by Hoare, Mills, and Francis (2013); Maz (2013); and Urquhart (2013). Some of the participants were interviewed more than once, with the responses in the initial interviews guiding the structure and direction of the subsequent interviews. I compared new data with previously acquired data while looking for differences and similarities. This comparison guided the direction of more participant recruitment in the current study. The tenet of the CGT approach is to give voice to the cancer survivors who were the participants in this study as suggested by as suggested by Charmaz (2014) and Urquhart (2013).

The collected data answered the RQ and subquestions regarding the perceptions of cancer survivors in Nigeria about the care that they received from their health care

providers during treatment. Transcribing the interview sessions was the first step in the data analysis and involved listening to the audiotapes several times to become more familiar with the data. I used NVivo v.10 to arrange, manage, and retrieve the data (Creswell, 2009; Rudestam & Newton, 2007; Silver & Lewins, 2014).

### **Issues of Trustworthiness**

I addressed several issues pertaining to the trustworthiness of the study during various phases of the research. I established trustworthiness by addressing issues about the credibility, transferability, dependability, and confirmability of the findings (Lincoln & Guba, 1985).

### **Credibility**

I improved the credibility of the findings by keeping detailed field notes and memos. I used reflexivity to show how my own interests, my profession as a primary health care physician, and my assumptions might have influenced the study. I engaged in debriefing sessions with my committee chair, committee member, and URR to discuss any evidence of researcher bias. I took the transcriptions of the interviews back to the participants to ensure that they agreed with their accuracy before I analyzed the data (Green & Thorogood, 2009). The theoretical group interviews with the 30 participants recalled in five small groups of six added to the credibility of the study.

Finally, I ensured the credibility of the study by obtaining quality data from the participants, analyzing the data correctly, and drawing the correct conclusions. Credibility was further ensured through my prolonged engagement with the participants during the study to develop an understanding of their experiences and perceptions, as

suggested by Green and Thorogood (2009). Meaningful interactions were developed during the interviews to give the study enhanced credibility.

### **Transferability**

Applicability of the findings to other contexts that is supported through evidence is known as transferability (O'Leary, 2004). These other contexts can be different participants, situations, and groups. Transferability is analogous to the concept of external validity that is used in quantitative research. Transferability of the findings in the study was ensured through detailed descriptions of the research context and methods (O'Leary, 2004). These descriptions helped to determine whether the findings could be applicable to other settings and target populations (Lincoln & Guba, 1985; O'Leary, 2004; Sutter, 2011).

### **Dependability**

Dependability in qualitative research is equivalent to reliability in quantitative research. The dependability of the study was enhanced through the use of several instruments to document the data: audiotapes of the interviews, field notes, and memos. I also used triangulation, a type of cross-validation of the data performed using multiple methods of data collection, to enhance the dependability of the study (Lincoln & Guba, 1985; Lodico, Spaulding, & Voegtle, 2010).

### **Confirmability**

Confirmability refers to the ability to demonstrate that the conclusions and the substantive theory derived at the end of the study reflect the researcher's interpretation of the data. My committee members conducted the confirmability audit. They scrutinized

the inferences to ensure that they were drawn from the data. They checked the appropriateness, clarity, and explanatory power of the codes used in the analysis. They went through my field notes, memos, transcriptions, and techniques to ensure that there was no significant degree of researcher bias at any stage of the study (Lincoln & Guba, 1985). Finally, I ensured the credibility of the study by maintaining complete field notes, preparing the transcriptions, triangulating the data, making frequent contact with the participants, and carrying out peer debriefing and expert auditing (Creswell, 2009; Jeanfreau & Jack, 2010; O'Leary, 2004).

### **Reliability**

In qualitative research, reliability indicates that the researcher's approach is consistent across other studies and projects (Creswell, 2009). I ensured that the reliability of the study was enhanced by keeping detailed field notes (O'Leary, 2004); using good-quality audio-recording tape; and transcribing the content of the tapes correctly (Creswell, 2009; O'Leary, 2004). I used NVivo v.10 manage the data in order to maintain the consistency of the coding process (Creswell, 2009; O'Leary, 2004; Silver & Lewins, 2014).

### **Ethical Procedures**

The Helsinki Declaration on ethical guidelines for conducting medical research with human participants required that I obtain informed consent from the participants (Creswell, 2009; O'Leary, 2004). I ensured that all information and data obtained during this study would not be disclosed in other settings without the consent of the participants (Miller, Mauthner, Birch, & Jessop, 2012; O'Leary, 2004). The published study will not

identity any of the participants or the sites where the study was conducted. The participants were identified through alphanumeric pseudonyms only. This study involved individuals who had experienced cancer and its treatment. I demonstrated empathy and understanding during the interviews to reduce the emotional impact of the interviews on the participants (O'Leary, 2004). As mentioned earlier, I will store all documentation securely, and only I will have access to it (O'Leary, 2004). I will maintain the anonymity of the participants, and I will store the data for 5 years, as stipulated by Walden University's IRB, before destroying them.

I successfully completed the human research training course of the NIH. I gained ethical approval from all relevant statutory bodies in Nigeria as well as Walden University's IRB (IRB approval #90-30-15-03553967) prior to collecting any data (Creswell, 2009; O'Leary, 2004). The concepts of truthfulness associated with doctoral research and the prohibition of dishonesty were emphasized to the participants.

### **Summary**

I conducted a qualitative study using the CGT approach to explore the perceptions of a sample of 30 cancer survivors about the delivery of care from health care practitioners in various cultural contexts. I recruited the participants by sending them an e-mail based upon a letter introducing the research topic, outlining their rights as participants, and providing them with information about the study protocol. I used purposive sampling to select participants who were cancer survivors and had diverse sociodemographic characteristics (Oppong, 2013).



I observed ethical considerations during all the phases of the study, beginning with the recruitment of the participants. As mentioned previously, I obtained approval from the chair of the board of trustees of an NGO in Nigeria as well as Walden University's IRB and the participants. I interviewed 30 cancer survivors and recalled them in five small groups of six participants in each group for theoretical group interviews. The semistructured interviews allowed me to obtain the perspectives of the participants about the care provided to them by health care providers while they were receiving treatment for cancer (Charmaz, 2014; Creswell, 2009). The interviews involved asking open-ended questions to facilitate the emergence of conversations directed by the participants (Charmaz, 2014; Creswell, 2009; Hesse-Biber & Leavy, 2010). The next chapter describes the results.

## Chapter 4: Results

### **Introduction**

The treatment of cancer has improved in developed and less developed countries over the last 3 decades. However, in most developing countries, the majority of the patients continue to depend on the financial support of family members and kinsmen (Chukwuneke, 2015). Most cancers are now treatable if diagnosed early, but the development of sophisticated treatment modalities for cancer also have resulted in side effects not previously known. In addition, the different MDTs caring for cancer patients have meant that many more health care practitioners are involved. I studied the perceptions of cancer survivors about their care in order to ensure the best treatment outcomes.

I used interviews to collect data on the perceptions of the care received from health care practitioners from 30 purposively selected survivors of cancer in Nigeria. The study was guided by one RQ: “What are the perceptions of cancer patients in Nigeria about the care delivered by their health care practitioners?”

I also used five subquestions to help answer the primary RQ:

1. How do major indices of survivors’ perceived quality of cancer care indicate positive or negative perceptions toward the care?
2. What do cancer survivors perceive as the desired goal of their care?
3. How do cancer survivors perceive the way through which the desired goal of their care is achieved?

4. What factors contribute to the different levels of survivors' perceptions about the care received from health care providers?
5. How can survivors' perceptions about the care received from health care providers be improved?

Included in this chapter are the results of the study, explanations of the data collection and analysis processes, and a discussion of the findings.

### **Setting**

Data collection and analysis were limited to the interview responses from 30 participants. This study provided initial insight into the way that cancer survivors in Nigeria perceived their care. The interviews were scheduled to be held over 4 days, but this time line changed because some of the participants had to return to their occupations and businesses. In addition, stipends promised to the participants had to be increased because the interviews took much longer than the time agreed to in the study information leaflet. One participant was told that her cancer had recurred, but she was still willing to participate in the study because she did not want to return the stipend.

### **Demographics**

To collect the required data for this CGT study in Nigeria, I had to understand the perceptions of the selected cancer survivors about their health care. I selected 30 cancer survivors who voluntarily agreed to participate in the semistructured, in-depth interviews. The participants were selected from among cancer survivors who had benefited from the services of a registered NGO for cancer survivors in Nigeria. The process for participant selection involved sending each potential participant an e-mail with a copy of the

research leaflet attached. The individuals who expressed an interest in participating replied to inform me of their willingness to join the study. The individuals whom I purposively selected were sent a copy of the consent form to study and sign. Those who were not selected to participate were politely informed via an e-mail. I contacted those who returned the signed consent by phone to schedule mutually acceptable interview times, dates, and locations. In accordance with the sampling processes described in Chapter 3, I selected participants from different sociocultural backgrounds, from urban and rural areas, and with diverse cancer diagnoses.

To facilitate communication with the participants due to my preference to use standard English for the interviews, I selected only individuals who were proficient in spoken English, as determined by their level of formal education. The 30 participants were eight male and 22 female Nigerians between the ages of 28 and 65 years at the time of cancer diagnosis. This information about gender reflected the fact that the issues faced by female patients might have been different from those faced by male patients. Specific demographics information follows: college degree ( $n = 18$ ) or senior high school level of education ( $n = 12$ ); married ( $n = 18$ ), divorced ( $n = 2$ ), widowed ( $n = 2$ ), separated ( $n = 3$ ), or single ( $n = 5$ ); employed ( $n = 11$ ) or unemployed ( $n = 19$ ); and major caregivers identified as relatives ( $n = 27$ ), friends ( $n = 1$ ), or themselves ( $n = 2$ ). The participants were from the main geopolitical zones of the country and belonged to different ethnic groups and tribes in Nigeria. The participants belonged to both the Christian and Islamic faiths, and all of them had received their medical care for cancer from hospitals in

Nigeria. I excluded cancer survivors who had travelled abroad for treatment from participating in this study.

All of the participants had different cancer diagnoses, all had received care in government-funded hospitals, and all had covered their own expenses. None of the participants had worked in the health care sector, and none of them had lost a close relative or friend to cancer. I did not want the participants confusing their own experiences with the experiences of deceased relatives or friends. There was no need to describe physical or other characteristics of the participants as part of this CGT because they had experiences within the same context, that is, from the same set of professionals who were bound by similar professional ethics.

### **Data Collection**

As mentioned previously, before collecting the data, I received permission to conduct the study from Walden University IRB and the board of trustees of a cancer support NGO in Nigeria, which allowed me recruit its service users for the study. After receiving approval from the chair of the NGO in Nigeria, I e-mailed the prospective participants a copy of the study leaflet with a letter of invitation to join the study. Once any of the contacted cancer survivors indicated their willingness to join the study, I e-mailed them a consent form to sign. Once I received the signed consent form, I contacted the selected participants by phone to schedule the interviews at convenient times and place.

The purpose of the study was to gain cancer survivors' perceptions about the care that they received from health care professionals in Nigeria while undergoing treatment.

The findings of this study might help to improve the care experience of cancer patients in Nigeria. The 30 participants were selected from the target population of survivors of different cancers in Nigeria.

Because this was a CGT study, I needed to select participants who had undergone treatment for cancer in Nigerian hospitals over the past 2 years but who were healthy at the time of the study. Other inclusion criteria included the ability to speak English language fluently, possession of a satisfactory level of formal education, and a willingness to sign the consent form. Exclusion criteria were cognitive or emotional health problems that could have prevented potential participants from giving informed consent or participating in the interview.

### **Interviews**

To collect the data, I conducted semistructured, in-depth interviews with the 30 participants between January 22 and January 29, 2016. All interviews were private and followed a face-to-face format. Participants were 22 women and 8 men; their mean age was 42 years ( $SD = 12$  years) I used the interview protocol approved by Walden University's IRB to maintain consistency in the way that I asked the interview questions and some spontaneous follow-up questions. The sample size was driven by the need to generate sufficient data to reach data saturation (Morse, 2007). Charmaz (2014) described data saturation as the point in the study when no new information emerges.

I interviewed some of the participant more than once, and each interview lasted approximately 45 minutes and was audiorecorded and transcribed, usually within 24 hours, verbatim. I read each typed transcription and coded important concepts within 3

days. I also took field notes also during the interviews and wrote memos at the end of each interview. I randomly selected 10% of the audiotapes and transcribed versions that were compared by an independent experienced researcher as a quality assurance measure of transcription accuracy. Participants also completed a demographics questionnaire and received a gift of an equivalent of \$5 USD for each interview. I also conducted theoretical group interviews in which I recalled six of the 30 participants at a time and briefed them on the ongoing analysis; and subsequently asked the five small groups to provide their insights on the emerging theoretical model from the data analysis. These theoretical group interviews also helped in the completion of the processes of data saturation, gathering of other relevant information from participants, termination of data collection, analysis, and memo writing (Morse, 2007).

### **Reflexivity**

My personal characteristics likely had some impact on the behavior of the participants during the interviews. Some of the participants asked if I were married or would consider marrying two or more wives, a common practice in Nigeria and other African countries. Some of the participants wanted to know about my children.

### **Data Preparation**

I listened to all of the interview audiotapes along with a Nigerian doctor and a trained nurse with years of health care experience. After the audiotapes were transcribed verbatim, I changed some of the confusing words in the transcriptions to facilitate their understanding by readers who are not familiar with Nigerian expressions. I also used alphanumeric identifiers to ensure the anonymity of the participants and to identify them

as I worked through the data analysis (e.g., RP1-F45-MM stood for Research Participant 1, female gender, age 45 years, and diagnosis of multiple myeloma).

### **Data Analysis: Coding Process**

I used the CGT approach, meaning that data collection was concurrent with data analysis until data saturation was reached. Because the data were so diverse, the entire data set was subject to open coding, followed by a process of grouping these codes called selective, or focused, coding and reworking them through theoretical coding. I analyzed the collected data using NVivo v.10, and I carried out the cognitive aspect of the coding process entirely. I used NVivo v.10 in the organization of the data, development of a coding schema, retrieval of coded data segments, and the writing of memos (Silver & Lewins, 2014).

After reading the initial six transcriptions several times, I coded them line by line, using gerunds as codes by searching for actions in each segment of the data to identify codes or units of meaning in the data (Charmaz, 2014). This process is known as open coding. I arranged the open codes using NVivo v.10. Initially, there were about 600 such open codes. Iterative checks between data and coding continued as line-by-line codes were gradually organized under more analytical codes (Urquhart, 2013).

As I reviewed the open coding, I generated memos describing the emergent concepts from the data analysis and the relationships among the concepts. I then grouped each of the open codes to form about 10 selective codes. This phase is known as focused coding in the CGT and selective coding in classical grounded theory (Charmaz, 2014; Urquhart, 2013).



Finally, I carried out the theoretical coding by conceptualizing how the substantive codes from the selective coding processes were related to each other using the theoretical codes from the code families, as proposed by Glaser in 1978 (as cited in Urquhart, 2013). The theoretical codes selected were the ones that fit with the emerging theoretical model. The generated hypotheses or theoretical concepts are integrated into a substantive theory by relating them to the literature in a process known as theoretical integration (Charmaz, 2014; Urquhart, 2013). Results of the current study showed that three theoretical concepts emerged from the data to develop the substantive theory on the perception of cancer survivors in Nigeria about the care received from health care professionals during treatment (Urquhart, 2013).

#### **Evidence of Trustworthiness**

To ensure the trustworthiness of the study, I conducted member checking. I gave the participants copies of the transcriptions of their interview responses for review. They were asked to make corrections to these transcriptions if they had reason to change their minds about anything or if they felt that I had misinterpreted their responses while transcribing them. This process was meant to enhance the credibility, reliability, and the validity of the in-depth interviews. Rigor was maintained through memo writing, repeated verification of the findings at every stage of analysis with the participants, an analytic audit trail, and the use of qualitative analytic software.

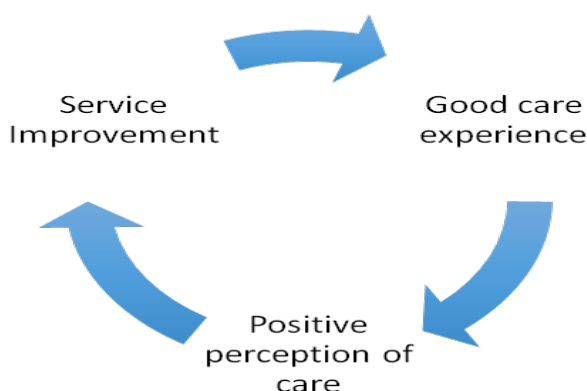
I was immersed with the data for a prolonged period and compared the procedures with those in other studies conducted by other students from Walden University and other reputable universities in the United Kingdom (UK), the United States, and Canada using

the same methodology. Conformability was enhanced by including direct quotes from the participants to illustrate the themes, core variables, and theoretical concepts. To further enhance the trustworthiness of the research, I used member checking during the coding processes, the debriefing, and the constant comparative analysis (Creswell, 2007).

### **The Emergent Theoretical Model**

The next part of this chapter introduces the three theoretical concepts or themes that emerged from the analysis of the data and provides an overview of the emerging constructivist theory. I also describe the emerging theoretical concepts from the theoretical coding process using a combination of composite and direct quotes. I explore literature that helps to explain the themes that emerged from the analysis of the data.

After completing the coding, memoing, and data collection, a substantive theory known as the PSG theory linking the different theoretical concepts or core categories of positive perception of care, service improvement, and good care experience emerged (see Figure 2). Only core categories or theoretical concepts were included in the theory (Urquhart, 2013). Overall, the grounded theory emerging from the data analysis showed how the concepts were cyclically related. In the following pages, I provide in-depth descriptions of the theoretical concepts of the model supported by excerpts from the transcribed interview responses. The transcriptions had undergone member checking to corroborate the theory.



*Figure 2.* Cyclical relationship of the emergent themes in the substantive theory.

### **Theme 1: Good Care Experience**

In Nigeria, poverty, the lack of proper public health screening programs, ignorance of the disease, nonavailability of needed medical personnel, and family decisions are the factors affecting the care experience, good or bad, of cancer patients (Chukwuneke, 2015). This view was supported by RP30-M42-TC, a 42-year-old male with testicular cancer:

I saw one doctor because of a swelling on my testicle. He told me it was hernia. He told me to go and look for money for operation on the hernia. I went to see my cousin for some financial help towards the operation. He took me to another doctor, who said it was not hernia, but testicular cancer after he did a scan on my testicles. He then referred me to the teaching hospital where I had my treatment.

Cancer patients often express concerns about inadequate pain and symptom relief (Chukwuneke, 2015). This assertion was supported by RP8-F32-BC, a 32-year-old female with breast cancer:

I had many injections and tablets for pains after the operation. The doctors and the nurses were kind to me. They gave injections when I had hiccups, they gave injections when I felt sick and was vomiting. They saved my life.

Cancer patients want respect for their dignity and independence, value the presence and support of family members, and expect good communication with their health care professionals (Holdsworth, 2015). This prior research finding was supported by RP5-F48-BC, a 48-year-old female with breast cancer:

The way we feel indirectly impacts the outcome of the care we receive. If we are satisfied with the information we received and the support given we automatically become happy with the care received. Many factors, including bedside manners of the health care professionals, emotional support they provide, clinical judgment, the way my family's anxieties were addressed, frankness and honesty of the health care professionals, support for my rehabilitation after my treatment were important to me.

Health care practitioners involved in cancer care are accountable for meeting standards of care required to enhance the public's trust in their abilities (Chukwuneke, 2015). They should make decisions that are in the best interests of their patients. These assertions were supported by RP26-F45-BC, a 45-year-old female who had already undergone three surgeries for breast cancer:

If my health is improved, I mean not merely physically but also emotionally, I feel that the care has been successful. This is the desired outcome I prayed for when I was starting my treatment. I believe God has a hand in my cure. The

efficiency of the different health care providers clearly lies in the way the care is provided, whether I am given complete information related to all aspects and also if nothing is hidden from me; the promptness of the care, including the operation. The nurses responded to my needs. The physiotherapists [and] the consultants in the radiology unit were very kind to me. They explained everything to me. After my discharge, my local doctor and his nurses cared for my wound.

Because cancer patients often are faced with uncertain prognosis and treatment outcomes, they are entitled to make choices regarding their own health (Chukwuneke, 2015). A national consultation with practitioners, commissioners, academics, and service user groups in the UK highlighted the need to respect the perspectives of cancer patients and their families while planning their care in MDT meetings (Holdsworth, 2015). Empowering patients is part of shared decision making. Health care professionals should provide care that is centered on patients' needs and wishes, and it is essential for patients to play an active part in their own care. Listening to patients, understanding their needs, and communicating clearly and openly ensures that patients understand what to expect from health care practitioners. The results are better working nurse-patient partnerships and more trusting therapeutic relationships during care.

Patients expect clear communication with their health care practitioners. They expect them to make sound clinical judgments, create a safe environment for care, respect their dignity, promote their autonomy, and involve them fully in all decisions relevant to their care (Radcliffe, 2014). These expectations were supported by RP19-M42-HL, a 42-year-old male with Hodgkin's lymphoma:

I did feel very happy with the level of autonomy. Cancer is a deadly disease in this country. The consultants explained everything to me. I was happy to follow their advice. The good thing was my cancer was caught early enough. I was given the opportunity to discuss with my family. They are the ones supporting me financially and otherwise. The consultants were very empathetic. I was treated like a human being, not a disease. I made my decisions on the care I received based on professional advice.

RP4-F38-BC, a 38-year-old female breast cancer survivor, concurred:

The treatment was successful because I feel better physically. The doctors looking after me were many. Some of them were professors with grey hair. They had other doctors working and learning under them. They explained everything about my illness to me and the treatment they were giving me. The doctors were emotionally supportive. They listened to me and asked me if I understood what they were telling me. They were very respectful to me. My consultants encouraged me to talk to others patients and my family. They treated all patients equally irrespective of religion, tribe, and financial status.

### **Theme 2: Positive Perception of Care**

Some literature has supported the belief that patient satisfaction with care might improve adherence to treatment, resource use, and the delivery of safe care to cancer patients (Chino et al., 2014). Patients with less instrumental support in terms of financial aid will express less satisfaction with the cost of their care. The provision of social support helps to improve the care experience of patients and the overall perceptions of the

care received. In addition, they are more likely to have positive perception of the overall quality of the care received (Chino et al., 2014). This view was supported by RP25-F42-BC, a 42-year-old female who had survived breast cancer:

My family carried the financial burden of my treatment. I needed to be told about the different stages of the care so that I could discuss with my family. My daughter was always there with me. I was allowed to discuss my care with my family after meeting with the consultant. Also supporting this view was RP13-F25-BC, a 25-year-old breast cancer survivor:

The doctors who looked after me were very concerned about me. They were interested in getting me better as soon as possible. They did not waste time in starting the investigations and the treatment. They explained every detail to me. Some of them were professors. That gave me a lot of confidence about their ability. The doctors and nurses were emotionally supportive. They never dismissed my concerns. They spoke simple English without medical jargons. RP15-F35-CC, a 35-year-old survivor of cervical cancer, commented:

I am happy I survived this disease. There were many influential and rich people who did not survive the same disease. I think I was lucky that the disease was diagnosed on time. The doctors and nurses who looked after me were very kind to me. They worked as a team. Everyone did his or her job to the best of their abilities. I was treated as a person and not a disease.

Enhanced patient experience is an important measure of PCC (Chino et al., 2014).

Considering the perspectives of cancer patients while planning their care results in positive perceptions of care by not only the patients but also their families (Chino et al., 2014). Patients are satisfied if their autonomy is respected and they are allowed to make choices about their health (Chukwuneke, 2015). This view was supported by RP6-F35-BC, a 35-year-old female survivor of breast cancer:

I was part of all decisions made about my treatment. The doctors and nurses were very respectful. I was given the opportunity to discuss with my family whenever I was not sure of what to say to them. The level of autonomy was very pleasing to me. I felt my emotions were well respected.

Even participants who paid for their own treatment were more particular about their contributions to their care plans; RP29-M65-PC, a 65-year-old male survivor of prostatic cancer, commented:

I had to pay for everything from my savings. I was carried along by the consultants all the time in the decision making as I was the one paying for the investigations. I must tell you I asked questions upon questions because I wanted to know that I was not spending money unnecessarily or spending money on investigations that will not help me. There was autonomy. The doctor encouraged me to talk to my family about the treatment plan. My family scheduled appointments with my consultants, [and they] came to ask questions about the treatment plan and the prognosis.

In general, patients who have negative perceptions of their care feel vulnerable, experience low self-esteem, become depressed, and have poorer health care outcomes.



They also are less likely to view their health care professionals favorably. Health care professionals whose patients have positive perceptions of the care provided feel accomplished, are satisfied with the work environment, and are less prone to clinical errors (Beck, 2014; Newcomer, Gould, Page, Donelan, & Perkins, 2014). Positive perceptions of care promote good doctor-patient relationships and assure cancer patients that their health care practitioners are not insulated from their day-to-day worries about their care (Desmond et al., 2014). These points were supported by RP3-M44-BCC, a 44-year-old male survivor of basal cell carcinoma:

Cancer is a serious condition which must be diagnosed and treated in time. Any delay can make a big difference to the outcome of the treatment. I want my doctors to be more concerned about giving me the best treatment and not about my ability to pay for the care. The doctors and nurses looking after me must be knowledgeable. That will be very reassuring that things will likely go well while they are looking after me. They must provide me with emotionally support. They must respect me and show me they understand my physical pains and anxiety about my diagnosis. They must provide me with all the information I need. They must tell me the truth about my condition at all time. They should tell when things are going wrong with the treatment. These were the qualities I expected from my health care providers, and I was not disappointed on any of these points.

These statements confirmed Desmond et al.'s (2014) finding of associations between satisfaction and age and SES.

### **Theme 3: Service Improvement**

There is a need for collaboration between secondary care specialists and primary care health care professionals to manage cancer cases. Working together will ensure the delivery of efficient care. It also can have a positive impact on care in a relatively short time because there will be more early diagnoses of cancer cases and better transition of care when patients return to the community after discharge from the hospital (Byrne, Xu, & Carr, 2015; Wilkinson, North, & Bourne, 2014). This information was supported by RP7-F37-CC, a 37-year-old female survivor of cervical cancer:

She advised that I see my doctor immediately. I went to my doctor to discuss the problem with him after work. He said there were many possibilities but that I needed to see the specialist for his opinion. He referred me to the gynecologist. I was lucky the gynecologist I saw in his private clinic was also working in the teaching hospital. I was examined, and they carried out investigations. The results came and my worst fears were confirmed. I was told it was cancer of the cervix.

This opinion was supported by RP2-F28-BC, a 28-year-old female survivor of breast cancer:

I was lucky my own was caught early. I was bleeding from my nipples. I said to myself, this was not normal. I went to my doctor to complain. He sent me to the teaching hospital. I was seen straight away by a junior doctor the same day. He then took me to the professor, who also examined me. They were very sympathetic. He ordered tests and when it was confirmed it was cancer, I was admitted for treatment.

Patients with cancer require prompt care because of the potential for curable illnesses becoming life-threatening conditions through risky delays. Disease processes and treatment regimens can put these patients at risk of serious infections. Cancer patients require rapid assessment and consistently available care (Beck, 2014). This view was supported by RP11-F41-MM, a 44-year-old female survivor of multiple myeloma:

In my own case, I was tired all the time. I was having pains all over my body. I thought it was malaria. I went to the chemist and bought some malaria tablets and indomethacin tablets. When I did not get better. I went to the doctor near where I live for tests. He then referred me to the teaching hospital, where I was told I had cancer of the blood called multiple myeloma.

Patient voice, if incorporated into the care plans developed by MDTs, can result in improvements to service. Active participation of patients in their care is a way of respecting their autonomy and preferences (Rowe & Nevin, 2014). This view was supported by RP18-F55-BC, a 55-year-old female survivor of breast cancer:

My consultant was patient and gave me all the possible information I needed about my illness and the treatment. He also told me about the complications of the treatment and my chances of successful outcome. He told me about support groups, and he encouraged me to discuss with my family. I will say he allowed me to take part in all the decisions, but I was not in the right frame of mind to argue about anything.

This view was supported by RP20-M52-LC, a 52-year-old male survivor of lung cancer:

I was coughing blood, which was strange to me, [so] I went to the emergency department. I spoke to the nurse, who immediately sent me to the medical resident on duty. He ordered an urgent X-ray that night, and the following day, other tests were ordered, and it was confirmed that I had lung cancer.

### **Literature**

In the tradition of CGT, the literature review developed throughout the process of data analysis (Charmaz, 2014). The emerging codes and categories guided the literature review. The constant-comparative method successively involves comparing data with other data, data with codes, codes with other codes, codes with categories, categories with other categories, and categories with concepts to generate more abstract concepts (Charmaz, 2014; Urquhart, 2013). The terminal stage of this analytic cascade happens when researchers compare the major themes comprising the substantive theory with the themes in theories found in the literature in order to show how the emergent substantive theory challenges, extends, or transcends other theories (Charmaz, 2014; Urquhart, 2013). Researchers have the responsibility of providing detailed literature reviews that fit the arguments present in the theoretical models or substantive theories emerging from their studies (Charmaz, 2014). This scholarly process adds credibility to research and helps to scale up the levels of the categories to that of formal, generalizable theories.

The substantive theory, or theoretical model, that emerged in the current study had not been tested for generalizability because it was a theory applicable only to this

study, so there was a need to do so by comparing it with the extant literature. Relating the substantive theory to other relevant theories will make the theoretical model or substantive theory clearer to the research audience and highlight areas for further research on the current research topic (Charmaz, 2014). In particular, by maintaining theoretical sensitivity, I was able to focus on studies of one theory each in the subspecialties of health promotion, health service management, and medical sociology (Urquhart, 2013). The emergent grounded theory was juxtaposed against these three theories from diverse areas of public health, looking at similarities and differences, clarifying the main ideas of the study, and showing how this study fit or extended these theories (Charmaz, 2014).

### **Theory 1: Watson's Theory of Human Caring**

Watson's theory of health care purports that by enhancing innate abilities of health care practitioners, they will be more driven to create caring environments where patients can have a good care experience (as cited in Desmond et al., 2014). This theory focuses on the caring relationships between health care practitioners and the patients receiving care from them (Desmond et al., 2014). This theory advises that health care practitioners need to be humane, present, attentive, conscious, and genuine. Watson's theory encompasses three conceptual categories, 10 carative factors or clinical caritas processes, and the transpersonal caring relationship (as cited in Nelms, Jones, & Treiber, 2011). The theory is now being used frequently as a philosophical and ethical guide for all health care professionals and nonclinical staff of health care institutions (Nelms et al., 2011). The theory serves as a model for conveying staff roles, values, and knowledge to patients and their families, and it has been used to improve communication to and among

the multidisciplinary team members and their diverse clinical (Watson, as cited in Nelms et al., 2011).

Patients encounter a variety of hospital employees, including phlebotomists, housekeepers, and catering and administrative or clerical staff, and these encounters, no matter how small or insignificant, can impact patients' overall perceptions of their care. How patients perceive their care is directly related to how satisfied they are with the entire patient experience. The literature has supported the finding that implementing Watson's theoretical model could improve the perceptions of staff about their integral role in patients' care experience and improve their job satisfaction. Both could enhance and improve patient satisfaction and could meet the needs of patients more efficaciously by creating a caring community in which individuals, groups, and systems relate in ways that represent holistic care. The theory is meant to care for and benefit patients, their families, and health care professionals (Desmond et al., 2014; Dudkiewicz, 2014; Nelms et al., 2011).

Watson's theory (as cited in Desmond et al., 2014) had important implications for the findings of this study. First, the theory helped to clarify the relationships among the three theoretical categories that emerged from the study, namely, service improvement, good care experience, and positive perception of care. The theoretical model or substantive theory that emerged from this study was similar to Watson's theory in having three theoretical concepts. This PSG theory, similar to Watson's theory, will help to improve the care delivered to patients, including cancer patients. In this way, Watson's theory helped the emergent theoretical model or substantive theory to achieve

generalizability. Furthermore, the PSG theory will help to generate interest in the literature on patient satisfaction and the provision of care by health care practitioners to cancer patients, particularly because the incidence of all types of cancer is rising in Nigeria (Eguzo & Carmazine, 2013).

### **Theory 2: Chronic Care Model**

The chronic care model (CCM) is a theoretical framework used to improve the care of individuals with long-term chronic conditions (Barker, De Lusignan, Baguley, & Gagne, 2014). The CCM has helped to guide the design of care protocols for people in the United States who have long-term conditions. Barker et al. (2014) suggested that care should be characterized by beneficial interactions between MDTs and patients through timely professional assessments, increased self-management by informed patients, prompt health care, and follow-up. Health care for chronic conditions and cancer requires planning in order to coordinate the actions of MDT caregivers (Barker et al., 2014).

The CCM summarizes the basic elements for improved care in health systems at the patient, community, and formal health care levels (Barker et al., 2014). Adopting this theoretical model of care for cancer patients ensures a positive effect on outcomes relevant to service use, treatment compliance, symptom improvement, and biological indices of symptoms amelioration in chronic conditions (Barker et al., 2014). The CCM is a widely used and evidence-based model that has been implemented in a variety of health care settings because it offers well-defined elements and service delivery components to emulate (Barker et al., 2014).

Norway has implemented service coordination reform using the CCM to improve the quality and effectiveness of health care because coordinated services were not being met adequately (Holm & Severinsson, 2014). Using this formal theory as a lens to view my emergent theoretical model helped to enhance its generalizability and show that the emergent grounded theoretical model can contribute to patient satisfaction and the improved provision of health care (Urquhart, 2013)

### **Theory 3: Plan, Do, Study, Act Model (PDSA)**

This change management model has four steps, namely, Plan, Do, Study, and Act. The proposed change in the health care delivery service is either acceptable or not, in which case the cycle starts again (Byrne et al., 2015; Donnelly & Kirk, 2015; Stikes & Barbier, 2013). This model was developed to test quality improvement ideas prior to full implementation (Byrne et al., 2015; Donnelly & Kirk, 2015).

The main purpose of this study was to generate a substantive theory on how cancer survivors in Nigeria perceived their care during treatment. This PSG theory comprised the cyclically related theoretical categories of service improvement, good care experience, and positive perceptions of care. This substantive theory is similar to the PDSA model, which also has cyclically related theoretical models: encouragement of learning, reflection, and validation.

### **Discrepant Cases**

There were no discrepant cases in the study. The sample was homogeneous, and the participants received care from government-funded cancer units of university teaching hospitals in Nigeria. The treating doctors were Nigerian-trained doctors, all of



whom had the same high level of specialist training. These Nigerian doctors headed the MDTs that planned, carried out, and supervised the treatment of these patients. The nurses from the same university hospitals also had been trained to the highest professional levels. The participant recruitment strategy targeted cancer survivors who were very articulate, were in good physical and mental health, and were willing to participate in the study.

### **Summary**

This chapter presented the responses from the participants to the eight interview questions. All of the participants had positive perceptions of their care by health care professionals in Nigeria while they were receiving treatment for cancer. The participants said that they were happy with the methods used by the health care professionals to help them achieve the objectives of their care.

In this chapter, I presented information about the study setting, participant recruitment process, relevant demographic information about the 30 participants, data-gathering process, and reflexivity. I also explained the data analysis, including the coding processes, the three codes involved, and the theoretical categories that emerged and how they were linked to form the theoretical model or substantive theory. Also presented were evidence of trustworthiness and measures to ensure the credibility, transferability, dependability, and confirmability to establish the worthiness of the study (Creswell, 2007; Lincoln & Guba, 1995). Each of the three theoretical categories making up the PSG theory was explained using quotes from the transcribed interview responses. I used the existing literature to justify the way these theoretical categories were linked to form the

PSG theory. Finally, three theories from the field of public health were discussed in depth and related to the PSG theory. In Chapter 5, I present a summary of the findings, discuss the strengths of the study and its contribution to the public health literature, explain the implications for positive social change, outline the limitations, offer recommendations for future research, and draw conclusions.

## Chapter 5: Discussion, Conclusions, and Implications

### **Introduction**

In this chapter, I present a summary of the findings of this qualitative study in terms of the three themes that formed the emergent theory and my interpretation of the findings using excerpts from the interviews. I also discuss the strengths of the study and its contribution to the public health literature. Finally, I explain the implications of the findings for positive social change, outline the limitations, offer recommendations for future research, and draw conclusions.

### **Summary of the Findings**

The purpose of this CGT study was to explore the perceptions of 30 cancer survivors in Nigeria regarding the care that they received from health care professionals while undergoing treatment. I wanted to understand these experiences to develop a theory based upon data obtained from the sample. I intend to disseminate the results in an effort to improve the skills and competency of health care professionals in the delivery of cancer care. I used the research paradigms of constructivism and critical humanism, a subtype of the interpretive paradigm to interpret the experiences of the participants, as suggested by Creswell (2007) and Rudestam and Newton (2007). I was able to observe the cancer patients in their cultural and social contexts by using these paradigms to interpret the experiences described by the cancer survivors themselves.

I concluded that the positive care experiences of the participants were the result of the health care professionals' respect for their autonomy as individuals capable of making decisions about their own health. The participants expected their health care professionals

to involve them in the planning of their care; be knowledgeable of and experienced in caring for their conditions; respect their families and friends; listen to their complaints; and provide immediate treatment to ameliorate symptoms of pain, nausea, vomiting, and hiccups. The participants also valued the support of their friends and families as factors in their positive care experience.

The participants considered early diagnosis, affordable treatment, competent health care practitioners, good communication with their health care professionals, honesty from health care practitioners, and good follow-up communication after discharge into the community setting as factors that enhanced their positive perceptions of care. They also considered positive perceptions of care as a way of enhancing compliance with treatment, screening programs, and the uptake of primary preventative measures. Results showed that the participants' positive perceptions of care enhanced their therapeutic relationships with health care practitioners as well as their confidence in the practitioners.

The participants considered service improvement crucial to the delivery of good care to cancer patients in Nigeria. They were pleased with the quality of cancer care available in Nigeria, particularly the measures to relieve pain, ameliorate other symptoms, and diagnose cancer early in terms of available screening programs. The participants did not believe that the availability of sophisticated health care technologies would improve cancer care if the disease was detected at a late stage. Positive care experiences led to positive perceptions of care, which led to improved services to cancer patients.

### **Interpretation of the Findings**

This section presents my interpretation of the findings in relation to the RQ and the subquestions: The interpretation is based upon the three theoretical concepts that were linked to form the substantive theory or the theoretical model that emerged from this study.

#### **Perceptions of Cancer Survivors in Nigeria About Care Received**

This study confirmed that good care experiences and service improvement led to the participants' positive perceptions of care received. RP17-F47-BC, a 47-year-old female survivor of breast cancer, said:

I had many injections and tablets for pains, infections, nausea, cough, hiccups, and vomiting after the operation. The junior doctors and the nurses were kind to me. They saw things from my own perspective. After my discharge, I still went back to the hospital for more treatment on the day ward.

The same view was shared by RP12-M58-PC, a 58-year-old male survivor of prostate cancer, who stated, "The way we feel indirectly impacts the outcome of the care we receive. If we are satisfied with the information we received and the support given we automatically become happy with the care received."

RP28-F49-LBC, a 49-year-old female survivor of large bowel cancer, noted:

I was always given the opportunity to discuss with my family before taking decisions. After all, they are the ones supporting me financially and otherwise. The consultants and junior doctors were very sympathetic. The nurses treated me like a human being and not a disease. After my discharge, my local doctor and his

nurses looked after my wound. The nurses were gentle when giving the painkiller injections.

These views were corroborated by previous research. For example, Geelen et al. (2014) conducted a qualitative study in the Netherlands and found that the health care professionals in their study believed that they needed to provide more information to cancer patients in order to improve the care experience. Hoerger et al. (2013) and Stajduhar et al. (2010) asserted that cancer patients preferred their health care professionals to communicate clearly and honestly with them to give them hope and to be respectful, caring, and empathetic. Van der Elst et al. (2013) found that patients described better nurses as being supportive, communicating better, and demonstrating professional attitudes and attachment toward patients and family members.

### **Ways to Improve Survivors' Perceptions of Care Received**

I found that health care professionals could improve patients' positive perceptions of their care by providing honest and frank communication, showing respect for patients and their families, having good knowledge about cancer care, and attending to the little things that really mattered to the patients. RP23-F39-BC, a 39-year-old female survivor of breast cancer, said, "I did feel very happy with the level of autonomy. Cancer is a deadly disease in this country. The consultants explained everything to me. I was happy to follow their advice."

RP21-F34-BC, a 34-year-old female survivor of breast cancer, commented:

I would appreciate more information about the care plan being given to the patients and also if the health care professionals are more empathetic towards the

patients. They should realize that patients are helpless, afraid of the outcome of their treatment, and the impact of adverse outcomes on their families and friends.

The above responses by the participants were supported in the literature. Larsson et al. (2011) found that involving patients in their care through the delivery of appropriate information by nurses, recognition of patients as competent individuals, and encouragement to participate in their own care improved their perceptions of their care.

### **Perceptions of Cancer Survivors About the Desired Goal of Care**

I found that the participants were aware that the prognosis of cancer can be unpredictable, even in countries where health care resources are unlimited. The goals of care, as perceived by the participants, included being free of symptoms, being cured of the disease, and being able to control the side effects of treatment. The participants considered the emotional support of families and health care professionals as important components of their treatment. Participants who thought that death from cancer was imminent wanted to be allowed to spend their last days with loved ones. The participants believed that achieving these goals depended on the communication skills of the health care professionals, the control of their symptoms and the side effects of treatment, and the inclusion of loved ones in their care.

The participants liked having MDTs implement their care plans. This preference was supported by some of the interview responses. RP22-F38-BC, a 38-year-old female survivor of breast cancer, said:

When I was told about the cancer diagnosis, I knew I had a major battle ahead of me. I knelt down and prayed. I told God to direct the doctors, nurses,

physiotherapists, pharmacists, radiotherapy and laboratory people that will look after me in the hospital and after my discharge. I prayed that they will make the right decisions about my care.

RP24-F36-BC, a 36-year-old female survivor of breast cancer, remarked:

I was initially reluctant to have my breasts removed by the doctors, but I agreed when the consultant explained that removing the breast was the only way of saving my life. After all, at my age, no man is looking at me again. I do not have to breastfeed again. My arms were swollen, but when I wear clothes, that is hidden... I called the nurses for painkillers each time I could not bear the pains anymore. I tied my headgears to cover my baldness. It was difficult, but I was prepared for everything.

RP27-F43-BC, a 43-year-old female survivor of breast cancer, asserted:

My only goal for all the money and time on the treatment was to be cured. I did not believe it was time for me to die at my age. My mother is still alive. I came with my two breasts, but now they are gone. I was bald, lost weight, but I believe it was all worth the trouble. The care was by the whole team. I believe they all contributed their own quota to everything. The doctors, the nurses, the physiotherapist, the radiologists, and the people serving food contributed to my treatment.

The participants' comments were supported by previous research in different parts of the world. Horvath et al. (2010) as well as Litton et al. (2010) examined MDT cancer care with a focus on physician and patient satisfaction. Both teams of researchers found



that improving communication, increasing efficiency, and building patient confidence led to improvements in patient care. They also found that the cancer patients preferred care that was delivered by MDTs. Peppercorn et al. (2011) studied three significant aspects of cancer care, namely, symptom management, disease-directed therapy, and attention to QoL.

### **Factors Contributing to Survivors' Perceptions of Care Received**

The cancer survivors in my study considered their care to be of high quality, especially if the health care professionals who were caring for them were empathetic, honest, intelligent, and respectful, and if treatment had been delivered in a timely fashion. The participants were aware that the prognosis of cancer depended on whether the diagnoses had been delayed, or not. They also knew that cancer that had been treated could return. All of the participants agreed that aggressive public health programs should be in place to detect cancers early. These results were supported by the participants' responses to the interview questions.

RP14-F46-BC, a 46-year-old female survivor of breast cancer, said:

The individual treating me must be knowledgeable and provide me emotional support. He treated all patients equally irrespective of caste, creed, and financial status. My doctors and nurses were all very good to me and possessed all these good qualities. I was absolutely confident in their abilities to see me through the battle with cancer.

In the same light, RP9-F51-BC, a 51-year-old female survivor of breast cancer, noted, "From what I have read about cancer, to achieve a total cure is a matter of good

fortune and early diagnosis. I was lucky: by chance, I found out I had cancer. There were others not so lucky.” The implication of these statements is that screening programs should be embraced by health care providers to increase the chances of surviving cancer.

The results also were supported in the literature. Peppercorn et al. (2011) asserted that care must encompass patients’ individualized assessment preferences, goals, and needs throughout the course of the illness. Tsianakas, Robert, et al. (2012) stated that the patients in their study considered the provision of information and their engagement in the treatment process as important features of effective care. Sorkin et al. (2010) found that perceptions of discrimination by cancer patients led to poor adherence to medication regimens, cancer screening recommendations, and health-related advice from health care professionals.

The conceptual framework of the current study was PCC. The core components of PCC are patients’ awareness of their conditions, available treatment options, feelings of respect and dignity in clinical encounters, and facilitation of involvement in the decision-making process (Epstein & Street, 2011a). This study, which led to the emergence of the PSG theoretical model, is an elaboration of this theoretical model. The results of this study indicated that cancer patients should have honest and frank communication with their health care practitioners, they should be given autonomy in their choice of treatment options, and they should be respected and treated with dignity.

### **Limitations of the Study**

There were many limitations in regard to the CGT approach used in this study of cancer survivors in Nigeria. The findings might contribute to increasing awareness and

understanding of cancer patients' perceptions of their care in the country. This study was about the perceptions of cancer survivors in Nigeria about the care that they received from their health care providers. The scope of the study was to describe the perceptions of care during treatment from 30 cancer survivors in Nigeria, which has a population of 170 million. There was no possibility of generalizing the results to other target populations.

The sample comprised individuals from a high-SES group with average education from a population with generally low health literacy levels (Eguzo & Carmazine, 2013). I selected the participants from a cancer support group who might not have represented the views of other cancer patients not in this particular group. In addition, the purposeful sampling method might have led to the exclusion of individuals who had care experiences different from those of the 30 participants.

To protect the identities of the participants, I did not ask for demographic information that was detailed enough to know whether they had all received treatment in one geopolitical zone in Nigeria. Familial or individuals histories of comorbid conditions like diabetes, heart conditions, and HIV/AIDS were not obtained from the participants. As a health care professional who has a good relationship with the support group and is practicing medicine in a developed country, I know that these two factors might have been a limitation in that the participants might have answered in ways that they thought would have met my expectations.

### **Recommendations for Further Research**

Suggestions for future research include investigating the perceptions of care of cancer survivors from Europe, the United States, and the Indian subcontinent. Future researchers might wish to study how the survivors of specific cancers perceive the care that they received from health care professionals. Future researchers should use qualitative methodologies other than the CGT approach, which has limitations in terms of sample size. Finally, future researchers should consider conducting quantitative studies, using surveys to produce more generalizable findings.

### **Implications for Positive Social Change**

The results of this study might be used to improve the care experiences of cancer patients and the skills of the health care professionals caring for them. This study might help the families and friends of cancer patients to realize the importance of their support in ensuring that cancer patients have positive care experiences while receiving treatment. This study also can help policymakers and politicians to plan and provide services that can benefit cancer patients. The results could have wider applicability to many disciplines, including oncology medicine, radiology, nursing, physiotherapy, and psychotherapy. In addition, the findings have implications for future research in Nigeria and developed countries because cancer is a global problem (Eguzo & Carmazine, 2013).

### **Conclusion**

Results of the study showed that cancer survivors in Nigeria who participated in this study were satisfied with the quality of care received from their health care professionals. As life expectancy continues to rise in Nigeria because of reductions in the

morbidity and mortality rates of communicable diseases, there is need to continue to train more health care professionals specializing in cancer (Eguzo & Carmazine, 2013). This ongoing training will ensure that the level of care enjoyed by the participants will be sustained for other cancer patients.

The substantive theory or theoretical model that emerged from this study can be integrated into more formal models in developed countries such as the United States, England, Canada, and Australia, where the model of health care is similar to that in Nigeria and health care professionals have similar training and professional ethos. The literature on cancer care demonstrated that the needs and expectations of cancer patients in these developed countries are similar to those of cancer patients in Nigeria. The issues of respect for patients and their families, courtesy from health care professionals, empathy, and patient involvement in clinical decisions are universal in their applicability across cultures and national boundaries.

Cancer is a significant public health issue in developed countries, even with the copious material and human resources available to treat the different types of cancer. The 30 cancer survivors who participated in this study benefited from early diagnosis, meaning that public health measures such as improved health literacy, better access to health care, and comprehensive screening programs are the most cost-effective ways of reducing cancer mortality rates.

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