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Experiences and coping strategies of oncology patients undergoing oral chemotherapy: First steps of a grounded theory study

Catherine Gassmann*, Nina Kolbe, Andrea Brenner

FHS St. Gallen, University of Applied Sciences, Rosenbergstrasse 59, 9001, St. Gallen, Switzerland

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ABSTRACT

Purpose: Chemotherapies are increasingly available for oral application. Previous studies have focussed on differences between orally and intravenously administered chemotherapies, mostly following quantitative designs surveying patients' preferences and adherence. The lived experience of patients undergoing oral chemotherapy has been rarely explored. Therefore, this study investigates how patients experience oral chemotherapy.

Method: We conducted open interviews with six patients and two spouses. Recruitment took place in the outpatient clinic of an urban Swiss hospital. Data collection and analysis followed the principles of Straussian grounded theory.

Results: The participants reported physical and emotional reluctance towards oral chemotherapy as well as toxic side effects. Feeling responsible emerged as a core phenomenon. All participants intended to adhere to the therapy although this was challenging because of the complex medication regimen. Belief in the effectiveness of the therapy was a strengthening factor.

Conclusions: All participants reported to be highly adherent to oral chemotherapy. Although they experienced some toxic side effects, they did not react. Monitoring toxicities and support in everyday life should be a core feature of care.

1. Introduction

Over the last decade the use of oral chemotherapies has increased (Goodin, 2007; Weingart et al., 2008). A quarter of roughly 400 antineoplastic agents are developed for oral administration (Weingart et al., 2008).

According to the American Society of Clinical Oncology and the Oncology Nursing Society, chemotherapy comprises all antineoplastic therapies for intravenous and oral administration (Neuss et al., 2013). By definition, oral chemotherapy includes all antineoplastic substances, cytotoxic as well as biological agents, that can be administered orally (Weingart et al., 2008). In recent years the approach to cancer therapy changed due to the development of new targets interfering with various phases of cell growth or cell division. This resulted in targeted therapies for oral administration (Aisner, 2007). Targeted therapies are substances blocking the growth and spread of cancer by interfering with specific molecules involved in the emergence or progression of cancer. There are several types of targeted therapies. Tyrosine kinase inhibitors can serve as an example. They interfere with the epidermal growth factor receptor (EGFR), selectively inhibit signal transduction and respond to the growth of tumor cells (Green, 2004; National Cancer Institute, 2014; Winkler et al., 2014). Another kind of cancer therapy available for oral administration is hormone therapy targeting hormone-sensitive breast or prostate cancer. By interfering with hormone production and action they slow or stop the growth of hormone-sensitive tumors (National Cancer Institute, 2015). Targeted therapies are mostly based on a cytostatic mechanism. Malignant cell proliferation is blocked and drug toxicity is tumor-specific. In contrast, cytotoxic chemotherapies interacting directly with DNA structure do not differentiate between tumor and non-tumor cells. Therefore, their drug toxicity is non-specific (National Cancer Institute, 2014; Winkler et al., 2014). Cytotoxic cancer drugs include DNA-alkylating agents, topoisomerase inhibitors and antimetabolites (Goodin, 2007). A cytotoxic cancer drug is defined as a therapeutic agent aiming to control the spread of cancer cells by killing cancerous as well as healthy cells (Winkler et al., 2014). Depending on the type of drug, different side effects

* Corresponding author.
E-mail addresses: catherine.gassmann@fhsg.ch (C. Gassmann), nina.kolbe@fhsg.ch (N. Kolbe), Andrea.brenner@fhsg.ch (A. Brenner).

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occur. Cytotoxic drugs available for oral administration comprise, among others, fluorouracil-derivates as capacitabine, prescribed in particular for colorectal and breast cancer and classified as prodrug of an antimetabolite (Cassidy et al., 2004; Van Cutsem et al., 2001). Each oral chemotherapy agent has its own toxicity profile (Aisner, 2007; Viele, 2007). Cutaneous reactions are frequently observed (Gutzmer et al., 2012), e.g. palmar-plantar erythrodysesthesia with an incidence of 6–64% (Nagore et al., 2000). Cutaneous toxicities can be dose-limiting. Depending on the severity of oral chemotherapy, they can cause mild side effects like pruritus or dysesthesia but they also can be lethal (Saltz et al., 2004; National Cancer Institute, 2010).

Side effects of cytotoxic oral chemotherapy are as hazardous and potentially dose-limiting as intravenously administered therapy (Schneider et al., 2011). Patients may think that taking a pill is less harmful than undergoing intravenous chemotherapy but this is a misconception (Moody and Jackowski, 2010; Weingart et al., 2008).

Orally administered chemotherapies have advantages and disadvantages for patients. On the one hand, they allow more self-control and fewer hospital visits are required. On the other hand, patients have to manage the chemotherapy regimen on their own and should react correctly in the case of toxic side effects.

Several studies have revealed patients' preferences for oral over intravenous chemotherapy (Borner et al., 2002; Catania et al., 2005; Liu et al., 1997; Schott et al., 2011; Oakley et al., 2010; Twelves et al., 2006). Reasons for preferring oral application comprised staying at home (Liu et al., 1997), experiencing less effects on everyday and family life (Schott et al., 2011), avoiding catheter-associated problems (Liu et al., 1997; Oakley et al., 2010), having more control over therapy, lower sensation of illness (Catania et al., 2005; Liu et al., 1997; Oakley et al., 2010) and improved quality of life (Borner et al., 2002; Twelves et al., 2006).

A pharmacological advantage of oral chemotherapy is the continuous exposure of tumor cells to the agent (Aisner, 2007; Sparreboom et al., 2002; Weingart et al., 2008). Strictly adhering to the therapy is of major importance for oral application. Dosage, time of intake and time intervals have to be followed exactly (Partridge et al., 2002; Spoelstra and Given, 2011). The term "adherence" traces back to Sackett and Haynes (1976) who defined it as "the extent to which a person's behaviour … coincides with the clinical prescription". According to Cramer et al. (2008) the terms *adherence* and *persistence* should be used to describe how patients follow their long-term medication regimen. Based on an extensive literature review, the authors define *adherence* as "the extent to which a patient acts in accordance with the prescribed interval and dose of a dosing", whereas *persistence* refers to the act of following a medical recommendation of continuous treatment for the prescribed length of time.

Generally, cancer patients are believed to be highly adherent because of the potentially life-threatening condition of their disease. Methods to assess adherence and duration of measurement vary between studies (Bassan et al., 2013; Partridge et al., 2002; Verbrugghe et al., 2013). A systematic review revealed adherence rates to oral chemotherapy between 53 and 100% (Partridge et al., 2002). Factors affecting adherence and non-adherence to oral chemotherapy have been widely explored. They can be related to the person (e.g. age, concern about symptoms, beliefs about the medication), to the therapy (e.g. treatment related side effects, medication regimen complexity), to the disease, to the physician, and to the health care system (e.g. communication) (Gater et al., 2012; Verbrugghe et al., 2013). Additionally, differentiation between intentional and unintentional non-adherence is required. Reasons for unintentional non-adherence are forgetting to take the medication or accidentally taking an overdose. Intentional non-adherence is caused by side effects or is emotion-related (Eliasson et al., 2011; Gater et al., 2012).

In the literature, the patients' perspective on experiences and challenges concerning oral chemotherapy has been explored mostly with quantitative designs. However, to our knowledge, only two studies have partly investigated the experiences of patients undergoing oral chemotherapy, particularly with regard to medication regimen and challenges associated with adherence and response to adverse effects of oral chemotherapy (Oakley et al., 2010; Simchowitz et al., 2010). Insight into these experiences is highly relevant as it should guide the nursing process. Therefore, this study intends to explore the experiences of patients undergoing oral chemotherapy and investigates the impact of oral chemotherapy on their daily life.

2. Method

2.1. Design

To address a patient-centered perspective, we chose a qualitative research paradigm as it allows focusing the experiences of the participants. Grounded theory as described by Strauss (1987) is an appropriate methodology for exploring how people experience the phenomenon under investigation and for explaining their experience. Strauss (1987) recommends a structured process of data analysis by applying the main analytical techniques of grounded theory such as theoretical sampling, constant comparison coding and categorizing in line with a paradigm model.

Theoretical sampling is one of the key aspects of grounded theory. It is applied to decide which data should be collected as concepts emerge (Corbin and Strauss, 2008; Strauss, 1987).

By using constant comparison researchers relate arising incidents with earlier incidents to look for similarities or differences. Conceptually similar incidents are grouped together as concepts. Concepts are codes representing groups of objects or actions with common but dimensionally varying properties (Corbin and Strauss, 2008).

2.2. Sample and setting

Recruitment of the sample took place in the oncological outpatient clinic of an urban Swiss hospital. Participants had to meet the following inclusion criteria: 1) age over 18 years, 2) diagnosis of a malignant neoplasm, 3) prescription of an oral chemotherapy currently or previously, and 4) German speaking. Eligible patients provided informed consent. Due to the sensitivity of the research topic, participants could receive psycho-oncologic support upon request. The ethics committee of the canton of Basel-Stadt approved the study.

2.3. Data collection

Open interviews are a suitable way of gaining insight into the lived experiences of persons affected (Kvale, 2006). Our interview technique was based on the autobiographic-narrative interview according to Schütze (1983), following the time line of the participants' personal histories. The first question was: "Could you please tell me how you experienced oral chemotherapy?" Further questions were added to stimulate the narrative flow concerning the course of oral chemotherapy, e.g.: "How did it start?", "What happened next?" and "What has happened since then?" The participants' initial narration was not interrupted. Remarks like "That's it" indicated that the first part of the story had come to an end. Further questions were asked to learn more about details and to gain deeper insight into patients'experiences (Schütze, 1983). Demographic and medical data were supplied by participants' self-