

Enabling sustained communication with patients for safe and effective management of oral chemotherapy: A longitudinal ethnography

ABSTRACT

Aims: To examine how patients received, understood, and acted upon healthcare professional communication about their oral chemotherapeutic regimen throughout their treatment.

Design: A longitudinal ethnographic study.

Methods: Over 60 hours of observational data were recorded, in the form of field notes and audio-recordings from interactions between 9 oncology doctors, 6 oncology nurses, 8 patients and 11 family members over a period of six months in outpatient departments within one hospital in Northern Ireland. Sixteen semi-structured interviews with patients and three focus groups with healthcare professionals were also carried out. This study took place from October 2013 to June 2016. Data were thematically analysed.

Results: Three themes were identified from the data. These were **initiating concordance through first communication about oral chemotherapy**; which focused on initial communication **during oncology consultations** about oral chemotherapy, **sustained communication of managing chemotherapy side effects**; which was about how communication processes supported timely and effective side effect management, and **un-sustained communication of oral chemotherapy medication-taking practice**; when patients and healthcare professionals failed to communicate effectively about chemotherapy medication-taking.

Conclusion: The two most important factors in ensuring the optimal management of oral chemotherapeutic medicines are early recognition and appropriate response to side effects and the maintenance of safe and effective **medication** administration. This study found that oncology doctors and nurses engaged in sustained communication about the side effects of chemotherapy but did not **focus** their communication **on** safe administration after the first consultation.

Impact: Based on this evidence, we recommend that **healthcare professionals who provide** oral chemotherapy for home administration should review their processes and procedures.

Healthcare professionals need to ensure that they embed frequent communication for the duration of treatment between themselves and patients, including open discussion and advice, about side effects and medication administration.

Key Words:

Oral Chemotherapy, Patient Participation, Oncology, Cancer, Communication, Medication-Taking, Patient Safety, Nursing, Ethnography, Qualitative Research.

INTRODUCTION

Cancer is a leading cause of death with almost 10 million deaths worldwide (World Health Organization, 2018). Colorectal cancer is the third most common form of cancer and its global burden is expected to increase by 60% to more than 2.2-million new cases by 2030 (Arnold et al. 2017).

There are several different treatment options recommended for people living with colorectal cancer including surgery, chemotherapy, targeted therapy, radiotherapy, or a combination of these approaches (Mitchell, 2013; National Institute of Clinical Excellence 2014). Chemotherapy treatment involves administering medications to impede cancer growth and kill cancer cells (National Comprehensive Cancer Network 2017). 5-fluorouracil is the most used type of chemotherapy for colorectal cancer, which is usually administered by a continuous pump as a 48-hour infusion, by weekly injections, or by daily injections (Marley and Nan 2016). However, in line with recent developments enabling oral administration of chemotherapeutic medications, the oral medication capecitabine has become widely administered internationally (Aguado et al. 2014).

Oral administration of chemotherapy affords patients and healthcare professionals several advantages. Patients can participate more actively in managing their chemotherapy. Convenience and flexibility in administering chemotherapeutic treatment are key advantages because patients can take their chemotherapy in tablet form at home (Oakley et al. 2010). It is important that patients can safely administer their chemotherapy and can recognise and report adverse effects of chemotherapy (D'Amato 2008; Oncology Nursing Society 2016).

Background

Acceptance of the impact of communication on patient medication-taking practices is long established (Marcus-Varwijk et al, 2019; Royal Pharmaceutical Society 1999; Stevenson et al. 2004; Tobiano et al. 2019; Young et al. 2019). However, limited empirical studies have focused on people living with cancer who administer their own oral chemotherapeutic treatments in the community (Mitchell et al. 2014). Current research about oral chemotherapy medication-taking practice has tended to focus on measuring adherence levels and subsequent implications for patients (Escalada & Griffiths 2006; Foulon et al. 2011; Given et al. 2011;

Partridge et al. 2002; Ruddy et al. 2009). This focus on adherence is understandable given the narrow therapeutic index of the medication and the fact that patients administer treatment without professional supervision.

Current research on chronic disease management **demonstrates** the importance of concordance in patient-healthcare professional communication (Hamann et al, 2014; Kehl et al. 2015; Mitchell et al. 2019; Siouta et al. 2016). Concordance involves patients and healthcare professionals **having** agreed decisions about treatment based on equal relationships (Mead & Bower 2002; Mitchell 2014; Royal Pharmaceutical Society 1999). Concordance is more likely to be achieved when communication focuses on what Jürgen Habermas (1984; 1987) terms the lifeworld of the patient. The lifeworld relates to a person's day-to-day experiences, perceptions, and interpretations of events, **and comprises** tacit and socially generated understandings that enable navigation of everyday life.

Since administration of oral chemotherapy often takes place without professional supervision, it is reasonable to consider the role of concordance as more important than usual. **This is because any deviation from healthcare professional guidelines could lead to harmful toxicity or poor treatment efficacy and even prove fatal (Lea et al. 2018).** While consideration of the lifeworld is important, it is also imperative that the patient **has** knowledge **and understanding about the importance of achieving** therapeutic treatment levels safely (Barry et al. 2001; Gilbar and Carrington, 2005). Errors with oral chemotherapy outside of the hospital are frequently reported in the literature (Given et al. 2011; Krikorian et al. 2018; Walsh et al. 2009).

This study explores how communication about oral chemotherapy affects patient knowledge and behaviour over time. This longitudinal approach was designed to illuminate the complex communication needs of people during the duration of their oral chemotherapy treatment.

THE STUDY

Aim and Objectives

The aim of this study was to examine how patients received, understood, and acted upon healthcare professional **communication** about their oral chemotherapeutic regimen throughout

their treatment. The objectives were to **examine** communication **over a sustained period; and to** establish patient understanding about oral chemotherapy, how **communicating about** self-administration is maintained over time **and** how communication regarding side effects management is maintained over time.

A full version of the research protocol can be found XXXX et al. (XXXX). **This study followed the standards for reporting qualitative research (SRQR) (O'Brien et al. 2014).**

Design

A **longitudinal** ethnographic approach was undertaken using observations, documentation analysis, semi-structured interviews, and focus groups (Hammersley & Atkinson 2007).

Ethical Considerations and Recruitment

This study was reviewed and approved by the Office of Research and Ethics Committee, Northern Ireland, June 2013 (Reference: 13/NI/0056), and by the Research Governance office of the relevant Health and Social Care Trust, June 2013 (Reference: 12144SP-SS). Written consent was obtained from patients, families, oncologists, and nurses who participated in the study. Recruitment occurred after patients' diagnosis of colorectal cancer and prior to their initial consultations at the oncology clinic. **If the researcher conducting data collection identified a potentially harmful practice during patient interview, the researcher informed the patient about this issue following the interview. Subsequently, the oncology team was also informed about any potential unsafe practices immediately by the patient via the 24-hour helpline. During consultations, the observer was also obliged to inform oncology doctors or nurses if a patient did not disclose unsafe practice that the researcher was aware of through previous patient interviews.**

Setting

The study setting was in an oncology outpatient unit, in a large 900-bed university teaching hospital in Northern Ireland. Patient participants were recruited from persons diagnosed with colorectal cancer and healthcare professional participants were those who worked with this

patient group. Further detail on inclusion and exclusion criteria can be found in supplementary file one.

Sample

All participants were purposively recruited. Patient participants had a first-time diagnosis of colorectal cancer, were prescribed capecitabine as part of their treatment and consented to observational data to be collected during their consultations with their oncologist and oncology nurses. Patient participants also consented to participating in two semi-structured interviews about their experiences at mid-treatment and post-treatment. Ten eligible patients received initial information about this study through their oncologists. Nine patients went on to receive information about the study from the research team, and eight patients agreed to take part and provided written consent to be part of this research study. All patient participants self-administered their treatment at home for a period of six months. Each patient participant attended a scheduled outpatient appointment with their oncology team every three weeks.

Consent was also obtained from 11 family members who attended treatment appointments with each patient. Healthcare professionals involved in patients' care were also invited to participate. All healthcare professionals involved in healthcare consultations received a comprehensive face-to-face presentation and detailed information sheet. Written consent was obtained from 15 healthcare professionals prior to commencement of the study. Healthcare professionals who participated in focus groups, which included doctors and nurses, also provided separate written consent. Focus groups took place three months after all observations and interviews were completed. Figure 1 provides an overview of the participant consent, recruitment, and data collection process.

Data Collection

The observer as participant stance enabled the researcher to observe participants during patient-professional consultations and actively interact with patients to encourage reflections about the consultation process (Bernard, 2006; Frey, 2018). The observer engaged with patients and family members during waiting periods before consultation. However, during consultations, there was no observer involvement. The type of data collected from observations involved audio recordings of consultations, field notes of patient and family visits to oncology clinics,

examination of information leaflets, and reflective journaling. Observational data collection occurred at five different time-points in the patient journey, which comprised the first (day 1), second (day 21), third (day 42), sixth (day 126) and final appointment (day 168) for each of the patient participants. These points of data collection were informed by an external expert steering group made up of oncologists, oncology nurses and people living with cancer. The reason for this schedule was because the expert steering group felt important communication about patient safety and oral chemotherapy would be more likely to occur early in the patient journey. Semi-structured interview with patient participants took place between the second and third appointment (approximately day 35-41) and a few weeks after the final appointment (approximately day 170-180). The location of these interviews was determined by the patient and they mostly took place at their own residence. Focus groups with healthcare professionals took place three months after full data collection of the final patient participant. These focus groups were held on hospital premises. Supplementary file two provides an overview of these data collection time points. The research team also carried out an examination of publicly available information leaflets given to patients during their consultations. Observations, interviews, and focus groups were recorded on a digital audio recorder. In addition, field notes and a reflective diary were recorded and maintained throughout this study and these were written up by the observer within 24 hours of each period of data collection.

Data Analysis

Data were analysed using inductive thematic analysis involving a six-step approach (Braun and Clarke, 2006). The first step was familiarisation of data through audio transcription by the first author. The next steps were coding of the data and subsequent generation of broad themes by the research team. Steps four and five involved the research team reviewing and defining their themes over several months. The final step in the process was writing up the findings (Braun and Clarke, 2006). The data were analysed by the research team using Habermas' Theory of Communicative Action (Habermas 1984;1987). In the context of this study, Habermasian theory was used to illuminate how patient-professional communication could achieve mutual understanding and recommended action.

Rigour of the Study

To improve the trustworthiness of research data, the four criteria of credibility, transferability, dependability, and confirmability were followed (Lincoln & Guba, 1985). Participants were provided with their interview or observation transcripts as a check of the data that were collected. Field notes were maintained about the research setting and comprehensive record-keeping was undertaken throughout the research process. **Regular team meetings ensured an appropriate audit trail was followed and reflexivity was addressed using a reflective diary that was updated after each episode of data collection. The reflexive diary was used as an ongoing check of the observer's experiences, perceptions and reflections, as a log of the data collection activities as they occurred and as a record of the methodological decisions made during the research process (Smith, 1999).** In addition, independent thematic analysis by all team members, discussed at team meetings, reinforced the robustness of thematic interpretation of the data.

FINDINGS

Data collection consisted of 40 separate observations totalling approximately 60 hours, examination of 19 information leaflets given to patients, 16 semi-structured interviews with patients in receipt of oral chemotherapy and three focus groups with oncologists and oncology nurses. Study participants included eight people receiving oral chemotherapy, eleven family members, nine oncologists and six nurses. This study took place from October 2013 to June 2016. Patient characteristics are described in Table 1.

Three themes were identified. The first theme **was initiating concordance through first communication about oral chemotherapy.** The second **theme was sustained communication of managing chemotherapy side effects, and the third theme comprised un-sustained communication of oral chemotherapy medication-taking practice.**

Initiating Concordance through First Communication about Oral Chemotherapy

All 8 patient participants and their families followed a similar journey throughout the course of their treatment (supplementary file three). The primary topic of conversation during first contact with patients always related to maintaining safety throughout oral chemotherapeutic treatment. The information communicated by oncology doctors and nurses included: the importance of medication adherence, **use of** the 24-hour helpline to report side effects; and

ways in which to manage diarrhoea, erythema, hair loss and rarer side effects. During this initial contact, healthcare professionals did not appear to refer to patients' particular lifeworld because communication was not personalised and all patients received the same information irrespective of the stage of their disease, gender, age or whether they had a family member present. Typical excerpts are highlighted as follows:

Doctor 1: Some patients on chemo become nauseous and we are going to prescribe you some anti-sickness medications as a precaution. (Observation 1: Patient 1)

Nurse 4: If you even feel tenderness on the soles of your feet, do be sure and tell us the next time. Use loads of moisturising cream [on feet] and if you are sitting in the house at night just kick off the shoes and let the fresh air go around your feet. (Observation 1: Patient 6)

Information given by healthcare professionals was supplemented by standardised information leaflets to patients about the side effects of chemotherapy. The usefulness of these resources was positively appraised by patients and their families as these provided a source of information that patients and family members could return, to if needed. However, the patient information leaflets were not specific to oral chemotherapy and therefore did not address the unique challenges associated with self-administration, adherence, and storage of medication.

While both physicians and nurses engaged in communication about management of side effects, practical details about how oral chemotherapy should be administered, handled, stored, and diluted were exclusively the role of oncology nurses. Throughout their practical demonstrations (for example demonstrating non-touch technique), oncology nurses routinely engaged with the lifeworld of patients. Patients engaged in shared decision-making about how they could correctly take their medication, which included safely diluting medication to overcome swallowing difficulties:

Beverley: Oh God, I will never be able to swallow those big things [oral chemotherapy].

Nurse 4: I can show you how to dissolve them if you like? It is straight-forward.

Beverley: No love, I will manage sure – will get used to them.

Nurse 4: Tell you what...I will show you how to dissolve these tablets and if you are finding them hard to take [swallow] then you know what to do? Sound good? (Observation 2, Patient 2)

Practical advice about oral chemotherapy medication-taking practice was not supplemented by any information leaflets. The absence of this supplementary information coupled with the fact that oncology doctors did not routinely discuss medication-taking appeared to deprioritise the issue from patients and family members. During the first semi-structured interviews, which occurred between appointments two and three, patients frequently recalled the importance of side effect recognition and management, but few reflected on information they received about medication-taking practice.

Hugo: The first consultation went well, but there was a lot to take in. The main message I got was that I needed to be vigilant when taking the tablets. Any temperature, or loose bowel motion or sickness...whatever...I needed to keep an eye on it and contact the cancer doctors immediately. (Semi-Structured Interview 1, Patient 8)

Estelle: The doctor was very serious, and I was trying to keep it light-hearted because I was nervous, you know? He [oncology doctor] was telling me about all the different ways that these things [oral chemotherapy] could kill me [laughs]! (Semi-Structured Interview 1, Patient 5)

Initiating concordance was a key goal of healthcare professionals during first contact with patients. Communication focused on reinforcing the importance of **recognising** side effects, **and managing** a medical-led consultation, a nurse-led consultation and **the** provision of supportive literature on chemotherapy. While medication-taking practice was an important part of nurse consultations, **the** lack of physician involvement and **specific** literature **on oral chemotherapy** meant that **medication-taking** did not appear to have the same significance **as recognising and managing side effects**.

Sustained Communication of Managing Chemotherapy Side Effects

After the first outpatient appointment, healthcare professionals consistently revisited the issue of patient recognition and management of side effects over the next six months. Reaffirming the patient and family knowledge base about the importance of side effects was the primary focus of professional-patient communication during all subsequent consultations.

Management of chemotherapy side effects was a shared responsibility between the healthcare professional team, the patient, and their families. **Open** dialogue between patients and healthcare professionals facilitated shared understandings about the impact of living with chemotherapy and spoke directly to the lifeworld of these patients. The disclosure of these side effects and the impact they caused the patient, enabled the oncology team to prescribe appropriate pharmacological and non-pharmacological approaches to support patients during their treatment, as highlighted in the excerpt from the reflective diary.

Diary: "what about your stomach, any diarrhoea?" Once Gerry disclosed this information, the doctor quickly drew up a treatment plan by prescribing ondansetron and offering dietary advice...Gerry's diarrhoea improved greatly for the remainder of his treatment and he eventually stopped his medication and managed his symptoms by his diet. (Reflection 3, Patient 7 & Reflection 6, Patient 7).

Early disclosure of side effects was associated with better management strategies. Patients who shared experiences about the impact of chemotherapy on their lifeworld were more likely to maintain concordance and reach a shared decision with healthcare professionals about what approach could work best for them. In the following excerpt, Dot the patient and her daughter Debbie discussed how challenges with sleeping were overcome.

Dot: I am getting there now but it was a long few weeks. I have sleeping tablets in case I need them, but I do not need these all the time. I do the relaxation exercises before bed.

Debbie: Yes, the [oncology] nurse was excellent, and she put us in touch with the counselling services which was very helpful. She recommended that my mum reads or takes a bath before bed to unwind and surprisingly those little things worked for her. (Semi-Structured Interview 1: Patient 4)

Facilitating shared discussions about side effect recognition and management relied on balancing the voice of the medical expert and the voice of the lifeworld. In the absence of patient-led disclosures about the side effects of treatment, healthcare professionals frequently used consultations to reaffirm the importance of recognising and managing the side effects of oral chemotherapy. Healthcare professionals defended this approach and conceded that because patients had to receive a large amount of information that was critical to their safety,

communication could often be repetitious and non-personalised. This issue was identified in focus groups with healthcare professionals.

Doctor 4: When you think about it, it is [giving information about oral chemotherapy] a bit like a script. We as doctors, it is the same for the nurses too, have a great deal of things to get across to the patient, you know? I do not think there is really another way to do it. (Focus Group 2)

An important element of sustaining communication about recognition and management of side effects, was the presence of a 24-hour helpline. Access to this helpline enabled patients to overcome any concerns about chemotherapy side effects through immediate communication with a healthcare professional. This mechanism acknowledged that patients had expertise in their body's experience of illness and that they could seek immediate medical expertise in the event of unmanageable chemotherapy side effects. Despite regular communication about this service, most patients were initially reluctant to engage with the helpline service when first confronted with a problematic side effect. Six patients and families did not use the 24-hour helpline and instead they contacted their own primary care physicians about the side effects of chemotherapy. Patients identified various reasons for contacting the primary care physician first. Most stated that they either thought side effects were not severe enough to contact the oncology team, or that they knew how busy the outpatient unit was and did not want to waste the time of the oncology team. However, even though most patients did not utilise the 24-hour helpline effectively in the first instance, professional feedback about the dangers of not informing the oncology service about side effects, combined with patients' own experiences of the negative consequences of not doing so, powerfully reinforced concordance on this issue during the course of treatment. By the conclusion of the study, all eight patient participants had contacted the help-line number at least once as illustrated in the excerpt that follows.

Carol: I was very sick to tell you the truth. I had a really high temperature, chest palpitations and could not keep anything down [vomiting]. I called my GP [General Practitioner] and eventually went to A&E [Accident and Emergency Department] ...It never really occurred to me that I should phone the helpline, but after that experience, I certainly did use that number [24-Helpline Telephone Number]. (Semi-Structured Interview 2: Patient 3)

Sustained communication about side effects was beneficial to patients throughout their treatment journey. The process facilitated safe treatment and empowered patients to engage in shared decision-making about managing side effects. It also recognised the need to persistently engage with patients' understandings and interpretations to ensure that their lifeworld concerns about being a burden did not prevent them from seeking appropriate help.

Un-Sustained Communication of Oral Chemotherapy Medication-Taking Practice

In contrast to the efforts made to sustain communication about the recognition and management of side effects, patients' oral chemotherapy medication-taking practice was seldom considered in professional-patient communication after the initial consultation. During the six-month course of chemotherapy, only two patients were explicitly asked about their adherence to their oral chemotherapy regimen by oncology nurses. Three patients did not correctly adhere to their regimen. Estelle missed several doses, Beverley missed six doses and Dot missed two doses over the course of their treatment. All these patients chose to take their missed dose along with their next scheduled dose of chemotherapy and **none intended to inform** their oncology team. An example of this situation is highlighted in the excerpt below.

Estelle: It won't do me any harm [missing a dose]...I just took double the next day... You have two weeks' worth of tablets, so any time I missed some, I just took some the next day when I remembered. (Semi-Structured Interview 1: Patient 5).

These occurrences demonstrated that, in the absence of sustained communication from the expert world of the **healthcare** professional about adherence, there were divergences of understanding about safe administration **that** could develop over time. These divergences of understanding were solved by patients in their own manner, which inevitably involved recourse to their lifeworld interpretations. Moreover, in the absence of consistent feedback between patients and healthcare professionals about adherence, there was no mechanism for **healthcare** professionals to identify and address potentially dangerous modes of self-administration.

Irregularities in dosage were not the only risky consequences of lack of sustained communication. Another problem related to medication-taking practice. Once again, healthcare professionals' communication with patients and families about how oral chemotherapy should be administered was not sustained beyond the initial appointment. In the

observations that occurred over the next six months, no oncology doctor or nurse checked to see how patients administered their oral chemotherapy. Four patients, Beverley, Carol, Estelle, and Hugo did not use safe handling practices as advised in their initial consultation, for example touching their chemotherapy with their hands, as noted in the excerpt that follows.

Carol: I think I asked her [Nurse 3] about touching them [the oral chemotherapy tablets] and she said to make sure my hands were clean beforehand and that you can touch your tablets and put them in your mouth, I think that is right...Then just hygiene all the time. Is that right? (Semi-Structured Interview 2: Patient 3).

Another example of poor medication-taking practice relates to Fiona who did not follow the initial instructions that she received from the oncology nurse about dissolving oral chemotherapy tablets to make swallowing the medication easier. According to the manufacturer guidelines, capecitabine tablets should never be crushed as the medication residue released from crushing is toxic.

Fiona: They [healthcare professionals] told me to dissolve them [oral chemotherapy], but I actually had to crush them [with a pestle and mortar] because it took them that long to dissolve in water and see every time I went in and looked at them – I was getting sicker and sicker because of the anxiety [of waiting to take that chemotherapy] so it made it worse. (Semi-Structured Interview 2: Patient 6).

The absence of direct input from the medical expert about medication-taking practice meant that patients used approaches based on their lifeworld understandings and interpretations, to overcome challenges that resulted from medication administration within the context of their everyday lives. During this study, several patients disclosed medication-taking practice that was not recommended by their oncology team, relating to the re-use of medication pots, storage of oral chemotherapy and use of water for swallowing tablets. While no participants in this study suffered harm, the paucity of professional-patient communication about medication-taking throughout the patient journey could be extremely dangerous for people self-administering their oral chemotherapy.

DISCUSSION

Initial professional communication focused on ensuring patients had the knowledge to safely self-administer their medication and recognise side effects of chemotherapy. As the patient journey continued, professional communication about management of side effects was sustained over time and this topic was consistently revisited. This consistent practical rechecking of understanding was very important as it supported patients receiving oral chemotherapy and their families, to identify harmful side effects, to take appropriate action throughout treatment and to facilitate overall concordance with the treatment regimen. Sustaining this communication also enabled healthcare professionals to engage with and influence the lifeworld perspectives of patients by, for example, repeated reassurance that using the helpline when experiencing toxicity was not a burden on cancer services. Such practice has been regularly reported and advocated in the international literature (Flannery et al. 2013; Oncology Nursing Society, 2016; Reid and Porter, 2011). In contrast, communication about medication-taking practice was not sustained beyond the initial appointment. This situation sometimes led to patient participants' unmediated reliance on their lifeworld understandings and interpretations in solving problems they faced in relation to the administration of their medication. This, in turn, led to patients engaging in some physically hazardous practices.

Concentration on side effects management is important because of the harmful toxicities associated with oral chemotherapy (Foulon et al. 2011; Jacobs et al. 2018). Healthcare professionals needed to equip patients with information about how to effectively recognise and report side effects in a timely manner. This information was arguably much more complex to communicate when considered alongside talking to patients about how to self-administer oral medication. It is possible that healthcare professionals assumed that patients could administer their own medication. However, literature reviews have identified poor adherence to oral chemotherapy as an important and recurring issue (Foulon et al. 2011; Given et al. 2011; Jacobs et al. 2018). Self-administration of oral chemotherapy is an activity performed away from the regulated and controlled context of the clinical arena. Instead, it occurs amid people's everyday lives, with all the challenges that these involve; challenges that can often impact on their treatment regimen. If they are left to their own devices, people will use the interpretative tools that they have developed within their own lifeworlds to respond to those challenges (Manias et al. 2007). The problem is that it is unlikely that these tools will fully equip patients to respond safely to the unique issue of administering highly toxic substances. Errors in administration have already been reported in previous research about oral chemotherapy (Escalada & Griffiths

2006; Foulon et al. 2011; Given et al. 2011; Jacobs et al. 2018; Mitchell et al. 2014; Partridge et al. 2002; Ruddy et al. 2009).

There is evidence from the work of Barry et al. (2001) that when patients share their lifeworld during consultations, it is beneficial. This facilitates the presentation of the patient's own personal agenda, for example their voicing of unique psychological or physical issues. The challenge for cancer care professionals is to help patients incorporate expertise in the administration of **potentially** dangerous chemotherapy into their lifeworld. In attitudinal terms, this requires an appreciation of the everyday challenges that patients face and a respect for their understandings of, and strategies to deal with those challenges. **Such practice has been acknowledged as a cornerstone of concordance in the context of management of other long-term conditions** (De Las Cuevas 2011; Manias et al. 2007; Manias 2010; Snowden et al. 2014). In behavioural terms, it requires sustained communication and support to ensure that patients' responses to the problems that arise of incorporating the administration of oral chemotherapy into their day-to-day lives is informed by appropriate technical knowledge.

LIMITATIONS

This study focused on patients who were diagnosed with colorectal cancer and prescribed one oral chemotherapeutic medication, capecitabine. Transferability of these findings to other cancer types or oral chemotherapeutic regimens may be limited because patients may be on multiple medications for treating their cancer condition. Similarly, the research reported on communication practices in one cancer centre. As such, its descriptive findings **may not be transferrable** to the practices of other units that dispense oral chemotherapy. A further limitation is the possible Hawthorne effect associated with the ethnographic methodology, whereby **healthcare** professionals and patients may modify their normal behaviours and practice due to being observed. The research team followed best practice to reduce the impact of these **limitations** as noted in the methodology and published protocol (XXXX et al. XXXX).

CONCLUSION

The two most important factors in ensuring the optimal management of oral chemotherapeutic medicines are early recognition and appropriate response to side effects, and the maintenance

of safe and effective **medication** administration. This study found that oncology doctors and nurses engaged in sustained communication about the side effects of chemotherapy but did not sustain their communication about safe administration after the first consultation.

Patients' responses to these differing approaches indicated that continuing communication over the full course of treatment had the effect of encouraging safe practice while the absence of continued communication increased the risk of dangerous practice by self-administering patients. The aim of that communication should be to establish concordance, which in turn requires healthcare professionals to appreciate the everyday challenges faced by patients and to engage respectfully but informatively **in** their responses to those challenges.

Based on this evidence, we recommend that **healthcare professionals who provide** oral chemotherapy **to patients** for home administration, should review their processes and procedures. **Healthcare professionals need to** ensure that they embed frequent communication for the duration of treatment between **themselves** and patients, including open discussion and advice, about side effects and **medication** administration.

FUNDING

This research has been funded by XXXX

CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

AUTHOR CONTRIBUTIONS

All authors meet at least one of the following criteria (recommended by the ICMJE: <http://www.icmje.org/recommendations/>) and have agreed on the final version.

References

- Aguado, C., García-Paredes, B., Sotelo, M., Sastre, J., & Díaz-Rubio, E. (2014). Should capecitabine replace 5-fluorouracil in the first-line treatment of metastatic colorectal cancer? *World Journal of Gastroenterology*, 20(20), 6092-6101.
- Arnold, M., Sierra, M., Laversanne, M., Soerjomataram, I., Jemal, A., & Bray, F. (2017). Global patterns and trends in colorectal cancer incidence and mortality. *Gut*, 66, (4), 683-691.
- Barry, C., Stevenson, F., Britten, N., Barber, N., & Bradley, C. (2001). Giving voice to the Lifeworld: More humane, more effective medical care: A qualitative study of doctor-patient communication in general practice. *Social Science and Medicine*, 53(4), pp. 487-505.
- Bernard, H. R. (2006). *Research methods in anthropology*. Lanham, MD: Altamira Press.
- Betcher, J., Dow, E., & Khera, N. (2016). Oral chemotherapy in patients with hematological malignancies—Care process, pharmacoeconomic and policy implications. *Current Hematologic Malignancy Reports*, 11(4), 288-294.
- Bettencourt, E. (2014). Oral chemotherapy—What your patients need to know. *Oncology Issues*, 29(6), 44-51.
- Birner, A. (2003). Safe administration of oral chemotherapy. *Clinical Journal of Oncology Nursing*, 7(2), 158-162.
- Borner, M., Schoffski, P., de Wit, R., Caponigro, F., Comella, G., Sulkes, A., Greim, G., Peters, G., van der Born, K., Wanders, J., de Boer, RF., Martin, C., & Fumoleau, P. (2002). Patient preference and pharmacokinetics of oral modulated UFT versus intravenous fluorouracil and leucovorin: A randomised crossover trial in advanced colorectal cancer. *European Journal of Cancer*, 38(3), 349-358.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- D'Amato, S. (2008). Improving patient adherence with oral chemotherapy. *Oncology Issues*, July/August, 42-45.
- De La Cuevas, C. (2011). Towards a clarification of terminology in medicine taking behaviour: Compliance, adherence and concordance are related although different terms with different uses. *Current Clinical Pharmacology*, 6(2), 74-77.
- Escalada, P., & Griffiths P. (2006). Do people with cancer comply with oral chemotherapy treatments. *British Journal of Community Nursing*, 11(12), 532-536.
- Felzmann, H. (2012). Adherence, compliance, and concordance; An ethical perspective. *Nurse Prescribing*, 10(8), 406-411.
- Flannery, M., McAndrews, L., & Stein, K. (2013). Telephone calls by individuals with cancer. *Oncology Nursing Forum*, 40(5), 464-471.
- Foulon, V., Schoffski, P., & Wolter, P. (2011). Patient adherence to oral anticancer drugs: An emerging issue in modern oncology. *Acta Clinica Belgica*, 66(2), 85-96.

- Frey, B. (2018). *The SAGE encyclopaedia of educational research, measurement, and evaluation*. London: Sage.
- Gilbar, P., & Carrington, C. (2005). Oral antineoplastic chemotherapy. *Journal of Pharmacy Practice and Research*, 35(3), 195-198.
- Given, B., Spoelstra, S., & Grant, M. (2011). The challenges of oral agents as antineoplastic treatments. *Seminars in Oncology Nursing*, 27(2), 93-103.
- Habermas, J. (1984). *The Theory of Communicative Action: Volume 1: Reason and the rationalization of society*. London: Heinemann.
- Habermas, J. (1987). *The Theory of Communicative Action: Volume 2: Lifeworld and system: A critique of functionalist reason*. Cambridge: Polity Press.
- Hamann, J., Lipp, M., Zapp, S., Spellmann, I., & Kissling, W. (2014). Psychiatrist and patient responses to suspected medication nonadherence in schizophrenia spectrum disorders. *Psychiatric Services*, 65(7), 881-887.
- Hammersley, M., & Atkinson, P. (2007). *Ethnography: Principles in practice (3rd edition)*. New York: Routledge.
- Jacobs, J., Pensak, N., Sporn, N., MacDonald, J., Lennes, I., Safren, S., Pirl, W., Temel, J., & Greer, A. (2018). Treatment satisfaction and adherence to oral chemotherapy in patients with cancer. *Journal of Oncology Practice*, 13(5), 474-485.
- Kehl, K., Landrum, M., Arora, N., Ganz, P., van Ryn, M., Mack, J., & Keating N. (2015). Association of actual and preferred decision roles with patient-reported quality of care: Shared decision making in cancer care. *JAMA Oncology*, 1(1), 50-58.
- Krikorian, S., Pories, S., Tataronis, G., Caughey, T., Chervinsky, K., Lotz, M., & Shen, A., & Weissmann, L. (2018). Adherence to oral chemotherapy: Challenges and opportunities. *Journal of Oncology Pharmacy Practice*, doi: 10.1177/1078155218800384.
- Lafata, J., Gratie, D., & Nguyen, B. (2018). Patient-clinician communication and oral chemotherapy adherence. *Journal of Clinical Oncology*, 36(15), suppl. e18849-e18849.
- Lea, C.S., Bohra, S., Moore, T., Passwater, C., & Liles, D. (2018). Exploring behaviors, treatment beliefs, and barriers to oral chemotherapy adherence among adult leukemia patients in a rural outpatient setting. *BMC Research Notes*, 11(843), doi.org/10.1186/s13104-018-3935-z
- Lincoln, Y., & Guba E. (1985). *Naturalistic inquiry*. Newberry Park: Sage.
- Manias, E., Claydon-Platt, K., McColl, G.J., Bucknall, T.K., & Brand, C.A. (2007). Managing complex medication regimens: Perspectives of consumers with osteoarthritis and health professionals. *Annals of Pharmacotherapy*, 41(5), 764-771.
- Manias, E. (2010). Medication communication: A concept analysis. *Journal of Advanced Nursing*, 66(4), 933-943.
- Marley, A., & Nan, H. (2016). Epidemiology of colorectal cancer. *International Journal of Molecular Epidemiology and Genetics*, 7(3), 105-114.

- Mead, N., & Bower, P. (2002). Patient-centred consultations and outcomes in primary care: A review of the literature. *Patient Education Counselling*, 48(1), 51-61.
- Marcus-Varwijk, A., Madjdian, D., de Vet, E., Monique, W., Mensen, M., Visscher, T., Ranchor, A., Slaets, J., & Smits, M. (2019). Experiences and views of older people on their participation in a nurse-led health promotion intervention: “Community Health Consultation Offices for Seniors”. *PLoS ONE*, 14(5), e0216494, <https://doi.org/10.1371/journal.pone.0216494>.
- Mitchell, G. (2013). The rationale for fractionation in radiotherapy. *Clinical Journal of Oncology Nursing*, 17(4), 412-417.
- Mitchell, G. (2014). Adherence to medications: Towards a shared understanding. *Nurse Prescribing*, 12(11), 564-569.
- Mitchell, G., Porter, S., & Manias, E. (2014). Adherence to oral chemotherapy: A review of the evidence. *Cancer Nursing Practice*, 13(4), 25-28.
- Mitchell, G., Porter, S., & Manias, E. (2015). A critical ethnography of communication processes involving the management of oral chemotherapeutic agents by patients with a primary diagnosis of colorectal cancer: Study protocol. *Journal of Advanced Nursing*, 71(4), 922-932.
- Mitchell, G., Porter, S., & Manias, E. (2019). From telling to sharing to silence: A longitudinal ethnography of professional-patient communication about oral chemotherapy for colorectal cancer. *Psycho-Oncology*, 28(2), 336-342.
- Neuss, M., Polovich, M., McNiff, K., Esper, P., Gilmore, T., & LeFebvre, K. (2013). Updated American Society of Clinical Oncology/Oncology Nursing Society chemotherapy administration safety standards including standards for the safe administration and management of oral chemotherapy. *Journal of Oncology Practice*, 9(2S), 5s-13s.
- National Comprehensive Cancer Network (2017). *Colon cancer*. Philadelphia: National Comprehensive Cancer Network.
- National Institute of Clinical Excellence (2014). *Colorectal cancer: Diagnosis and management*. London: National Institute of Clinical Excellence.
- O'Brien, B.C., Harris, I.B., Beckman, T.J., Reed, D.A., & Cook, D.A. (2014). Standards for reporting qualitative research: A synthesis of recommendations. *Academic Medicine*, 89(9), 1245-1251.
- O'Neill, V., & Twelves, C. (2002). Oral cancer treatment: Developments in chemotherapy and beyond. *British Journal of Cancer*, 87(9), 933-937.
- Oakley, C., Crowe, M., & Johnson, J. (2010). Introducing the United Kingdom Oncology Nursing Society's (UKONS) position statement on oral chemotherapy. *European Journal of Cancer Care*, 19(S1), 1-4.
- Oncology Nursing Society (2016). *Oral adherence toolkit*. Philadelphia: Oncology Nursing Society.

- Partridge, A., Avorn, J., Wang, P., & Winer E. (2002). Adherence to therapy with oral antineoplastic agents. *Journal of the National Cancer Institute*, 94(9), 652-661.
- Reid, J., & Porter, S. (2011). Utility, caller, and patient profile of a novel chemotherapy telephone helpline service within a regional cancer centre in Northern Ireland. *Cancer Nursing*, 34(3), 27-32.
- Royal Pharmaceutical Society of Great Britain (1999). *From compliance to concordance: Achieving shared goals in medication taking*. London: Royal Pharmaceutical Society of Great Britain.
- Royal Pharmaceutical Society (2019). *Professional guidance on the administration of medicines in healthcare settings*. London: Royal Pharmaceutical Society of Great Britain.
- Ruddy, K., Mayer, E., & Partridge, A. (2009). Patient adherence and persistence with oral anticancer treatment. *CA: A Cancer Journal for Clinicians*, 59(1), 56-66.
- Siouta, E., Muhli, U., Hedberg, B., Brostrom, A., Fossum, B., & Karlgren, K. (2016). Patients' experiences of communication and involvement in decision-making about atrial fibrillation treatment in consultations with nurses and physicians. *Scandinavian Journal of Caring Sciences*, 30(3), 535-546.
- Smith, B. (1999). Ethical and methodologic benefits of using a reflexive journal in hermeneutic-phenomenologic research. *Image: Journal of Nursing Scholarship*, 31(4), 359-363.
- Snowden, A., Martin, C., Mathers, B., & Donnell, A. (2014). Concordance: A concept analysis. *Journal of Advanced Nursing*, 70(1), 46-59.
- Stevenson, F., Cox, K., Britten, N., & Dundar, Y (2004). A systematic review of the research on communication between patients and health care professionals about medicines: The consequences for concordance. *Health Expectations*, 7(3), 235-245.
- Stewart, B., & Wild, C. (Editors) (2014). *World cancer report 2014*. Lyon: International Agency for Research on Cancer.
- Tobiano, G., Chaboyer, W., Teasdale, T., Raleigh, R., & Manias, E. (2019). Patient engagement in admission and discharge medication communication: A systematic mixed studies review. *International Journal of Nursing Studies*, 95, 87-102.
- Walsh, K., & Dodd, K., Seetharaman, K., Roblin, D., Herrinton, L., Von Worley, A., Usmani, G., Baer, D., & Gurwitz J. (2009). Medication errors among adults and children with cancer in the outpatient setting. *Journal of Clinical Oncology*, 27(6), 891-896.
- World Health Organization (2018). *Cancer fact sheet*. Geneva: World Health Organization.
- Young, A., Tordoff, J., Leitch, S., & Smith, A. (2019). Patient-focused medicines information: General practitioners' and pharmacists' views on websites and leaflets. *Health Education Journal*, 78(3), 340-351.