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**From telling to sharing to silence:
A longitudinal ethnography of professional-patient communication about
oral chemotherapy for colorectal cancer**

ABSTRACT

Background: Healthcare professionals are encouraged to promote concordance, a shared agreement about prescription and administration of medications, in their communication with patients. However, there is a paucity of research regarding the impact of communication about self-administered oral chemotherapy. The aim of this study was to examine the changing dynamics of communication through the patient journey from diagnosis of colorectal cancer to post treatment of chemotherapy.

Methods: Over 60 hours of observational data were digitally recorded from interactions between 15 healthcare professionals, 8 patients with colorectal cancer prescribed Capecitabine and 11 family members over a six-month period in outpatient departments within one hospital in the United Kingdom. Sixteen semi-structured interviews were conducted with patients during and after their treatment. Three focus-groups were carried out with healthcare professionals. These data were analysed using thematic analysis.

Results: The patient journey followed a path of four distinct phases: autocracy, physiological concordance, holistic concordance and silence. Initially, communication was medicalised with patients occupying a passive role. As patients continued their journey, they took a more active role in their treatment discussion by leading consultations and sharing their priorities of care. At the end of treatment, patients felt isolated and unsupported when they were discharged from their oncology team.

Conclusions: Communication about oral chemotherapy is not a static process; it evolves to take account of changing clinical requirements and growing patient confidence in dealing with their cancer. Different stages in the treatment journey indicate the need for different approaches to communication.

1| BACKGROUND

Cancer is one of the leading causes of morbidity and mortality with more than 15 million new diagnoses each year¹. 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 and 1.1 million deaths by 2030². Presently, the most common ways to treat colorectal cancer are surgery, radiotherapy, targeted therapy, chemotherapy or a combination of these³. Over the past decade, administration of chemotherapy has changed with a growing number of patients now receiving their chemotherapy in the form of oral medication that can be swallowed as opposed to traditional intravenous prescription⁴. For example, 5-fluorouracil can now be administered as the oral medication Capecitabine for treatment of colorectal cancer⁵. A recent Cochrane review highlighted no differences in overall survival rates of colorectal cancer patients who received oral chemotherapy versus intravenous treatment⁶. As a result, there is a greater focus on people self-managing their chemotherapy due to concerns about patient safety issues in terms of self-administration and reporting of side effects.

Healthcare professionals are encouraged to promote shared decision-making, mutual understanding about expectations of treatment and equitable communication with patients in effort to enhance medication-taking practices of patients^{7 8 9}. Research has shown that mutual consideration of these aspects results in better treatment outcomes in the form of increased patient satisfaction, a higher likelihood of patient involvement in the consultation process, improvement in patient knowledge about their treatment and prognosis, more effective medication-taking practice from patients' and enhanced medication adherence^{9 10 11 12 13 14 15}¹⁶. These aspects are important component of the concept known as concordance.

A number of studies have examined the impact of communication on patient medication-taking practices but limited empirical studies have focused on people living with cancer who administer their own oral chemotherapeutic treatments in the community^{17 18}. Current research about oral chemotherapy medication-taking practice has tended to focus on adherence to the regimen and subsequent implications for patients^{19 20 21 22 23} with limited consideration on the role of concordance between patients and healthcare professionals^{24 25 26}^{27 28 29}.

Much of past research on healthcare professional-patient communication about medications has also involved an examination of communication at a single point in time^{9 30 31}. There has been no known published research which has examined the changing dynamics of communication throughout the patient journey from early diagnosis of cancer to post-treatment of chemotherapy. Examining communication practices over time can uncover changes in the communication needs of patients during their treatment journey.

This paper seeks to address these gaps in the literature by using a longitudinal methodology to examine the specific experiences of communication for patients taking oral chemotherapy and by considering to what extent concordance is important during consultations.

2| METHODS

A longitudinal ethnography was undertaken using diverse data collection methods including non-participant observations, documentation analysis, interviews and focus groups.

Ethnography enabled the research team to build familiarity and rapport with participants, to examine comprehensively the communication processes between individuals, and to follow patients and families over a prolonged time. The methodology enabled immersion in participants' lives and facilitated understandings about the complexities of their social interactions. Ethnography was chosen by the research team because its central ethos is concerned with observation of cultural practices; in this case, how health professionals and patients interacted with each other about oral chemotherapeutic treatment. We examined the processes of communication between healthcare professionals, patients and family members in managing the oral chemotherapeutic medication Capecitabine. This study was funded by the Department of Employment and Learning in Northern Ireland.

2.1| Ethics

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).

2.2| Context and Consent

The study took place in an oncology outpatient unit, in a large university teaching hospital in Northern Ireland. All patient participants consented to collection of observational data

during their consultations with their oncologists and to participate in two semi-structured interviews about their experiences mid-treatment and post-treatment. Consent was also obtained from family members who attended treatment appointments. All healthcare professionals involved in the observed healthcare consultations received a comprehensive face-to-face presentation and detailed information sheet. Written consent was provided by 15 healthcare professionals prior to commencement of the study. This process enabled the research team to audio-record communication between healthcare professionals and patients. In addition, the healthcare professionals who participated in focus groups, which included doctors and nurses, provided written consent to be involved in focus-groups. Information about context, consent and data collection processes are illustrated in supplemental appendix 1.

2.3| Patient Recruitment and Sampling

Participants were recruited from persons diagnosed with colorectal cancer and prescribed capecitabine tablets. We chose colorectal cancer for this investigation as it is a cancer for which oral chemotherapy is already well established⁵. Supplemental appendix 2 notes the inclusion and exclusion criteria of participating patients.

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. Patient participants administered their own treatment away from the hospital setting for a period of six months. The capecitabine regimen comprised eight cycles and consisted of two doses of capecitabine per day for a period of two weeks with the third week being reserved as a medication-free period. Each patient participant visited an oncologist at the end of each three-week cycle for review.

2.4| Data Collection

We carried out observational data collection at five different time-points in the patient journey. These occurred during the first (day 1), second (day 21), third (day 42), sixth (day 126) and final eighth appointment (day 168) for each of our 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. Data collection consisted of 40 separate observations totalling approximately 50 hours, examination of 19 information leaflets given

to patients, 16 semi-structured interviews with patients in receipt of capecitabine (at around day 60 and day 200) and three focus groups with pertinent health professionals (including oncologists and nurses). Participants included eight people receiving capecitabine, eleven family members, nine oncologists and six nurses. A greater number of healthcare professionals were recruited to this study, compared to patients, because patients interacted with multiple healthcare professionals. This study took place from October 2013 to June 2016. Patient characteristics are described in Supplemental appendix 3.

2.5| Data Analysis

Observations and interviews were recorded by a digital audio recorder. These data were transcribed verbatim by the research team (GM, SP & EM). Field notes comprising observational data were also written up by the observer within 24 hours of each period of data collection (GM). All these data were analysed using the process of thematic analysis which included familiarisation with data, generating initial codes, searching for themes, reviewing themes, defining themes and producing the report (GM, SP & EM) ³².

2.6| Trustworthiness

To enhance the trustworthiness of data we followed the four criteria of credibility, transferability, dependability and confirmability ³³. 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. Reflexivity involved discussion between the research team (GM, SP & EM) about how their interests or biases could impact their collection and interpretation of the data.

3| RESULTS

Following thematic analysis, we found four themes related to the patient journey throughout their treatment. These were autocracy, physiological concordance, holistic concordance and silence.

3.1| Autocratic Communication Processes

Data collection began at the first chemotherapy outpatient appointment when participants met the oncology physician and oncology nurse. During this first encounter, communication was almost entirely led by healthcare professionals who concentrated on medical aspects of treatment such as how to administer capecitabine safely, how to recognise side-effects and when to contact a 24-hour chemotherapy help-line. A typical example follows in this excerpt.

Doctor 2: So, you will have 24 weeks of the tablets, delivered in 8 cycles, each lasting 3 weeks. The 3 weeks will consist of 14 days on and 7 off. You will take your tablets twice, once in the morning thirty minutes after breakfast and once in the evening thirty minutes after dinner

Gerry: Right, Ok.

While patients appeared passive and spoke infrequently during their first appointment, they were highly satisfied about this style of communication. Patients perceived that healthcare professionals provided them with the knowledge to competently self-administer capecitabine. The following excerpt demonstrates how Carol was confident about what she should do if she experienced side-effects.

Researcher (GM): So, what happens if you get any of these side-effects?

Carol: You must let them know and they will advise you if it is good or bad or send you to your doctor or come in because they have all the treatments here. She said if you didn't ring them in time, you know it makes matters worse for them and their treatment and you might need your tablets reduced or something like that.

While patients reported high levels of satisfaction, healthcare professionals were more neutral. Healthcare professionals acknowledged that patients had to receive a large amount of information about their regimen and it was important the information was understood. During focus-groups, participants suggested that information about chemotherapy could often appear scripted, with healthcare professionals working their way through a list of side-effects.

Doctor 4: I suppose it does sound 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 don't think there is really another way to do it.

3.2| Physiological Concordance

This theme presents findings from patient participant consultations from appointment two until the fourth or fifth appointment, a period of approximately three to four months. In these consultations, it was more common for patients to lead communication about their experiences on chemotherapy by, for example, opening communication with healthcare professionals, asking questions and bringing conversations back to their own life. During this stage, healthcare professionals and patients collectively prioritised physiological and biomedical aspects of treatment in their shared communication, as illustrated by Estelle's third outpatient appointment.

Estelle: That is the thing I am dreading – going away on holiday and having sickness and not enjoying myself!

Doctor: Well we will be giving you more chemo...or...more anti-sickness home with you but if you are sick, despite them or if you have problems about keeping food down – that is one of the things you can ring and ask us about or get someone to ring for you.

During this period, family members of patients were also encouraged to share communication with healthcare professionals during consultations by asking questions about treatment. This is evident in the following excerpt between Debbie, daughter of patient Dot, and the oncologist.

Debbie: But then when you read that leaflet that you give us with that stuff [medication for nausea and vomiting], it says to take it regularly [Doctor interrupts]

Doctor: Yes regularly.

Debbie: With your chemotherapy tablets...we didn't know.

Doctor: Yeah...it is kind of working out really what is the best thing [dose] for you because for some people the queasiness won't be an issue at all and therefore we would say you probably would not need to take the anti-sickness tablets at all – but it depends on the person.

The first semi-structured interviews with patients and their family members took place between appointments three and four. Patients and their family members expressed satisfaction with the communication they received from the healthcare team up until this point. Patients highlighted that communication principally focused on establishing if they had side-effects, how serious these were and whether combative treatment (such as loperamide for diarrhoea, antiemetic medication for nausea, analgesia for pain or steroidal topical creams for erythema) or dose reduction was the most appropriate course of action.

During these consultations our field notes illuminated the importance of non-verbal communication between the healthcare professional team, patients and their family. Through our observations, we considered that good non-verbal communication was an important facilitator for shared communication. Excerpts from our diary fieldnotes on the importance of non-verbal communication are shown in supplemental appendix 4.

3.3| Holistic Concordance

This theme presents findings from patient participant consultations from around appointment five onwards, which was about months four to six of the patient journey. In addition to comprising biomedical aspects, this theme demonstrated how patients and families communicated about psychosocial issues of chemotherapy management. This dialogue took the form of expressing sadness, uncertainty and anger about living with cancer, sexual dysfunction, hair-loss and adjustments required for going back to work in the future. During her 7th appointment, Dot expressed fear about losing her hair because of her chemotherapeutic treatment. Despite nearing the end of her treatment regimen, the oncology nurse validated these concerns by offering psychosocial support and practical advice.

Dot: I am just anxious about my hair...and maybe going bald.

Nurse: Now sometimes, it will thin a wee bit, no-one else would notice only you: a couple of wee hairs on your brush or pillow. But even if that happens and you are unhappy with that we can get you a wig which is almost exactly the way your hair is...so don't worry and if you want a wig at any stage or you are concerned about that we can organise that anyway.

This theme was representative across seven patient participants. Only one participant, Gerry, did not appear to move away from physiological concordance during his treatment journey. Gerry was different from other patients in this study because he was the only participant who

did not have a family member come with him to his appointments. Gerry stated that this was because he did not want to be a burden to his family, who he did not tell about his cancer or treatment until after chemotherapy concluded.

3.4| Silence

The final theme related to patients' feelings once their treatment concluded. During this period patients felt isolated and unsupported at the end of their treatment. This was because once patient participants completed their treatment, they were no longer required to see their oncology team every three weeks and instead they would be followed up in six months to a year later. Therefore, there was not any opportunity to communicate post-treatment anxieties to an oncology team. In the excerpt that follows, Amanda highlighted how the absence of communication left her uncertain.

Amanda: I suppose the only negative thing is, while I don't want to be running up and down to the hospital, you are sort of sitting at home thinking – “is everything ok?” or “is it not ok?” I took a bug last week and I was thinking is this just a normal bug or is there something else wrong – that kind of thing because the symptoms are very, very similar to what I had before without the pain...so...I am trying to work out what is good for me to eat and what is not good for me to eat. I know doctors can't say because every patient is different...it's just I feel I need to go to a GP (General Practitioner) and ask to see a dietician or something. I feel a bit lost in that area afterwards. But I know they can't keep having you come down as well.

These experiences were echoed by all eight patients in their final semi-structured interview, around six weeks after the final consultation.

4| DISCUSSION

Current guidelines on communication about medications are often under-pinned by the concept of concordance^{6 9 28}. Recommendations for clinicians highlight the importance of collaborative communication, shared decision-making and an equal power dynamic^{6 28 29}. This study illustrates that such recommendations, while commendable, do not consider the developing dynamic of communication needs over time. Communication is not a static process; it evolves to take account of changing clinical requirements and growing patient confidence in dealing with their condition.

In this study, in the early stage following cancer diagnosis, the central goal of consultations with healthcare professionals was to educate patients and their family about the practicalities of oral chemotherapy. Patients and their families spoke highly of the competence of their oncology team at this stage of their journey. Furthermore, and perhaps unexpectedly, was finding that managing side-effects was often the only priority of consultations for the patient, their family and healthcare professionals. For all participants, the biological needs of patients tended to supersede psychological, social and spiritual needs. This tendency is not reflected in both the chronic disease and oncology literature, which emphasises the importance of holistic care at all stages of the treatment journey ^{7 8 9 24 25}.

As patients became more familiar with their treatment regimen, they began to take greater control of their consultations. Initially, this control manifested as an increased focus on the physiological side-effects that the patient was experiencing and how these could be medically managed. Communication from healthcare professionals was subsequently directed on the physical impact of chemotherapy and side-effects, such as diarrhoea, nausea, vomiting, and erythema, and the ways in which these side-effects were managed by pharmacological interventions. There was less consideration by all concerned on psychological or social concerns during this stage of the journey. These forms of medicalised communication have traditionally been widely critiqued within medical literature ^{34 35}. Despite these critiques, patients and their family members frequently commended their attending healthcare professionals in relation to their communication. Furthermore patients clearly declared a willingness to focus their own communication on their medical needs in the early stages.

Towards the end of their journey, patients were facilitated to discuss their experiences of taking chemotherapy in the context of their own life through topics like; managing hair loss, going on family holidays, attending social events, returning to work and managing fatigue. Healthcare professionals supported patients to talk about their unique psychological and social experiences in the context of their treatment. This finding highlights the benefit of holistic communication and is reflective of current oncology research ^{36 37 38 39}.

At the end of treatment, patients felt they faced an uncertain future because regular communication with their healthcare professional team had come to an end. This feeling of uncertainty is reflected in the National Cancer Survivorship Initiative's published report

where it states that 47.3% of survivors expressed fear of their cancer recurring and 19% of colorectal cancer survivors reported difficulty with their bowel function following recovery⁴⁰. The study results suggest that the fear regarding cancer recurrence is a common experience which may intensified by the absence of regularly scheduled oncology communication.

4.1| IMPLICATIONS

Most patients expressed high level of satisfaction throughout the entirety of their treatment journey. In addition, patients consistently stated that they were able to adhere to their regimen, maintain safety and report any side-effects in a timely manner. In contrast to the literature that suggests the need for holistic concordance from the outset, the study findings lead to the conclusion that different stages in the treatment journey indicate the need for different approaches to communication. Specifically, patients initially require a firm foundation of practical knowledge in order to become competent in the management of their oral chemotherapeutic regimen before they are in a position to engage in equal communication with their attending healthcare professionals.

A key problem in communication identified in the study was its cessation following the completion of treatment. Rather than feeling confident in continuing their journey without regular medical input, patients felt isolated, worried and unsure. The almost complete transfer of autonomy to them at this stage through the reduction of professional input was not therapeutically beneficial. This reduced input indicates a need to reconsider the level of communication and support that patients receive following completion of chemotherapy treatment.

To our knowledge, this research represents the first longitudinal investigation of communication about capecitabine or any other oral chemotherapeutic agent. Further research should examine the dynamics of communication on more complex oral chemotherapeutic regimens for conditions other than colorectal cancer. Research on the changing dynamics of communication throughout the patient journey will support healthcare professionals in understanding the priorities, for their patient groups, when communicating about oral chemotherapy.

4.2| LIMITATIONS

This study focused on people diagnosed with colorectal cancer who were prescribed Capecitabine at one oncology unit in the United Kingdom. Therefore, transferability of these findings to other settings, cancer types or oral chemotherapeutic regimens may be limited. A further limitation, inherent in all ethnographic research, relates to the Hawthorne effect and observer bias. As reported, the research team followed best practice to reduce the impact of these limitations. The research study had a low proportion of male patients (n=2) compared to female patients (n=6). Because of this gender imbalance, it was more difficult to make comparisons to communication processes and the journey that men and women experienced. Finally, the voice of the pharmacist was not captured in this study because pharmacists did not have routine involvement with patients.

5| CONCLUSION

The recent emphasis on the importance of concordance is to be welcomed. However, much of the current literature does not reflect the nuances and complexities of communication involved in the administration of oral chemotherapy. This study has shed light on these dynamic complexities, and has demonstrated the appropriateness of evolving modes of communication, involving the gradual enrichment of discourse from a point where factual information about the physical aspects of the therapy is imparted unidirectionally, through the stage where these aspects are discussed equally, to the point where social and psychological issues are added to topics of discussion. It also points to the need for communication between patients and professionals to continue beyond the stage of active treatment.

CONFLICT OF INTEREST

The authors have no conflict of interest to declare.

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Supplemental Appendix 1: Patient Consent and Data Collection Process



Supplemental Appendix 2: Inclusion and Exclusion Criteria

<i>Inclusion Criteria</i>	<i>Exclusion Criteria</i>
<ul style="list-style-type: none"> ➤ Participant must have a diagnosis of primary colorectal cancer. ➤ Participants who speak English fluently. ➤ Participants who have not been previously diagnosed with cancer (i.e. this represented the first time the person had presented with cancer). ➤ Participant must have been prescribed the oral chemotherapy medication, Capecitabine, as part of their treatment and must not have previously received chemotherapeutic treatment. ➤ Prescription of oral chemotherapy must have been used as a means of curative or life-longing treatment. ➤ Participant must have been taking their oral chemotherapeutic medications outside of the hospital setting. ➤ Participants who had a performance status of 0-1 based on World Health Organization Criteria. ➤ Participants who were over the age of 18 years old and were able to provide written and informed consent. 	<ul style="list-style-type: none"> ➤ Participants who had multiple cancers. ➤ Participants who lived in a nursing home facility. ➤ Participants who were being treated with oral chemotherapy for palliative purposes. ➤ Participants who had already registered in another trial or research study.

Supplemental Appendix 3: Patient Participants

Name (Pseudonym)	Age	Occupation	Family Involved in Study (Pseudonym)	Relationship Status
Amanda	28	School Teacher	Angela (mum) & Alan (brother)	Single
Beverley	78	Retired	Belle (sister) & Bryan (brother)	Widowed
Hugo	73	Retired	Heather (daughter)	Widowed
Carol	62	Retired	Colin (husband)	Married
Dot	74	Retired	Donald (husband) Debbie (daughter)	Married
Estelle	48	Unemployed	Erin (daughter) Elaine (daughter)	Married
Fiona	57	Shopkeeper	Fred (husband)	Married
Gerry	49	Taxi Driver	N/A	Recently Separated

Supplemental Appendix 4: Diary Excerpts on Non-Verbal Communication

Diary: “In my opinion the most impactful moment of the observation (Hugo, observation 2) came when the male oncologist put his right hand on Hugo’s left shoulder for about 30 seconds and assured him that he [Hugo] would be supported throughout his whole cancer journey by the oncology team. At that moment it seemed to me that this non-verbal gesture made more impact on all the words that had been spoken up until now. That hand on the shoulder seemed to connect Hugo to the doctor and woke him from his passive state. As the consultation seemed about to end, Hugo began communicating and asking questions of his doctor, the first being what sort of food was important to eat when his appetite was low. From my perspective as a man, observing the male doctor and the male patient...I felt warm and assured by the doctor.”

Diary: “It was clear to me that this nurse had done this [provide education about oral chemotherapy] many times before. Carol listened when the nurse spoke – she [the nurse] did all the non-verbal things that I was taught to do as an undergraduate nurse, she maintained eye contact, she checked that Carol understood what she was saying, she nodded and smiled at appropriate times and kept good open body language throughout proceedings. The nurse even considered her environment – she had arranged the chairs in a circle prior to us coming in so that it felt like an inclusive process. I thought that the non-verbal skills that the nurse exhibited really enhanced the actual communication about the oral chemotherapy which took place between Carol, her husband Colin and the oncology nurse.”