Health care professional-patient communication about oral chemotherapy: An ethnographic study

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Introduction

- Cancer is one of the leading causes of morbidity and mortality with more than 15 million new diagnosis each year.

- Presently the most common ways to treat cancer are surgery, radiotherapy, chemotherapy or a combination of these.

- With regards to chemotherapy, treatment is traditionally administered to patients intravenously.

- Over the past decade a growing number of patients are receiving their chemotherapy in oral form.

Introduction (2)

- Healthcare professionals are encouraged to promote shared decision-making, mutual understanding about expectations of treatment and equitable communication with patients in effort to enhance the medication-taking practices of patients.

- Research has shown that mutual consideration of these aspects results in better patient and treatment outcomes in the form of:
    - increased patient satisfaction
    - higher patient involvement throughout the consultation process
    - improvement in patient knowledge
    - more effective medication-taking practice
    - greater levels of medication adherence

Research Gap

- Plethora of research on the impact of communication on patient medication-taking practices **BUT** limited empirical studies which have focused on people living with cancer who administer their own oral chemotherapeutic treatments in the community.

- Current research about oral chemotherapy medication-taking practice has tended to focus on adherence to the regimen and subsequent implications for patients

Sample

- The study took place in in an oncology outpatient unit, in a large university teaching hospital in Northern Ireland.

- Participants were recruited from persons diagnosed with colorectal cancer.

- We chose colorectal cancer for this investigation as it is a cancer for which oral chemotherapy is already well established.

- To determine how individuals were involved in decision-making, we stipulated that all participants had to be taking capecitabine, an oral chemotherapeutic agent, for their treatment.

Methodology

- 8 patients, 12 care partners, 4 consultant, 5 doctors & 6 nurses were recruited

- Data was collected from a total of 40 observations, 16 semi-structured interviews & 4 focus-groups

Methodology (2)

1. Screening

2. Non-Oncological Medical Intervention

(Often Surgical)

3. Diagnosis

4. 1st Oncology Outpatients Consultation

5. Treatment Plan with Oncologist

6. Patient Chemotherapy Assessment *(Researcher present)*

7. Patient Discharge with Oral Chemotherapy (*Researcher present*)

8. Outpatients Review after 3 weeks (*Researcher present*)

9. Continuation with treatment, usually 8 cycles. (*Researcher present*)

Methodology (3)

1) Observation at ‘Patient Assessment Clinic’. (Day 1)
2) Observation at ‘Patient Outpatients Appointment 1’. (Day 21)
3) Semi-Structured Interview at Patient Home following second cycle of Capecitabine. (Day 35-41)
4) Observation of ‘Patient Outpatients Appointment 2’ (Day 42)
5) Observation of ‘Patient Outpatients Appointment 5’ (Day 105)
6) Observation of ‘Patient Outpatients Appointment 8’ (Day 168)
7) Semi-Structured Interview at Patient Home following final cycle of Capecitabine. (Day 170-180)
8) Focus-Group/Semi-Structured Interview with Health Care Professionals following collection of all patient participant data.

Phase One: Autocracy

Outpatient Appointment 1

- Scripted Patient Education:
  - Safe Administration of Oral Chemotherapy
  - Side-Effects of Chemotherapy
  - Management of Side-Effects

Phase Two: Facilitation

Outpatient Appointment 2-5

- Balancing Communication Processes
- Largely Medicalised Focus

Phase Two: Facilitation

Excerpt: Debbie/Observation 3

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: Yes regularly.

Debbie: I thought, well maybe they have given you 28…you are maybe meant to take 2 a day [for the 14 day cycle of Capecitabine].

Doctor: Yeah

Debbie: With your chemotherapy tablets…we didn't know, so that is why…

Doctor: Yeah…it is a little bit, it is kinda working out really what is the best thing 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.

Phase Three: Equality

Outpatient Appointment 6-8

- Patient-Led Communication
- Holistic Focus & Support

Phase Three: Equality

Excerpt: Estelle/Observation 5

Estelle: Well I haven't really spoken…I can talk to them ones [to daughters]…just emotionally I am crying all day.

Doctor: Do you not think you are coping well?

Estelle: I am coping to a certain extent – I just want to lash out. I am angry.

Doctor: With life in general or…

Estelle: No it could be with anybody, I just want to lash out and get the anger out. You know the way you get angry and ask why did it happen to you? Just have to cope with it…it will come out of me.

Doctor: Yeah, it is normal to feel like that.

Phase Four: Silence

Post Treatment

- Detachment of the Support Systems
- Fear of Cancer Returning
- Uncertainty About Future Appointment Times

Phase Four: Silence

Excerpt: Amanda/Semi-Structured Interview 2

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 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.

Discussion

- Communication Not Static – Transitions of Care
- Patient Needs Point of Knowledge Before True Voice Can Be Heard
- Autocratic Communication Should Not Be Critiqued Automatically

Discussion (2)

- Impact of Environment Pre-Consultation

- Post-Treatment Expectation That Patient is Ready To Be Alone – They Are Not

- Change of Patient Involvement Over Time is Significant

Conclusion

Key Question

How Do We Help Accelerate The Process To Shared Communication?