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Exploring perspectives of significant others on patients' experiences of cancer services.

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The associated file with this output contains a poster presentation and a slide presentation used at the symposium, which have been incorporated into a single file on this repository.

EXPLORING PERSPECTIVES OF SIGNIFICANT OTHERS ON PATIENTS' EXPERIENCES OF CANCER SERVICES

A. Brincat¹, A.Tonna¹, P. Vella Bonanno², D. Stewart³, A.E. Weidmann⁴

¹Robert Gordon University, Aberdeen, Scotland ²University of Strathclyde, Glasgow, Scotland

³Qatar University, Doha, Qatar ⁴University of Innsbruck, Innsbruck, Austria



BACKGROUND

AIM

- Globally, there has been growing concern that patients are not receiving appropriate cancer care based on their needs.
- Efforts were made towards better quality of care to meet patients' needs and expectations.
- Despite this, healthcare systems are required to operate with decreasing resources as a consequence of the overall economic context.

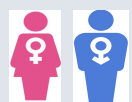
To explore the perspectives of significant others regarding cancer care experiences of patients receiving antineoplastic medicines for colorectal cancer

METHOD

- **A longitudinal qualitative study over a 6 month period**
- Patients initiating treatment for colorectal cancer with either FOLFOX for 12 cycles or XELOX for 8 cycles (n=16) at the national oncology centre in Malta were asked to nominate at least one significant other; that is a person who in their opinion was highly involved in their care
- **Setting:** 113-bed national oncology hospital in Malta
- **An interview guide** was compiled, reviewed by an expert panel and pilot-tested
- **Two in-depth semi-structured interviews** conducted at patient's initiation and completion of treatment (24 weeks interval)
- **Interviews audio recorded and transcribed verbatim** in denaturalised approach, with 10% random sample of transcripts undergoing accuracy check
- **Data analysed by 2 researchers independently** using an interpretative phenomenological approach
- **Key themes** identified and illustrated using representative quotes

RESULTS

Demographics



12

4

Relationship to patient	
Sibling	3
Spouse	6
Offspring	5
Niece	1
Healthcare professional	1

Theme 1: Patients' experiences of cancer services

Theme 2: Healthcare professionals' communication with patients and others

Theme 3: Recommendations for services

At initiation of antineoplastic medicines (cycle 1)

- Significant others and patients were overall satisfied with cancer services within the healthcare system, with negative experiences mainly related to misdiagnosis

- Being truthful about cancer diagnosis was perceived differently, with some considering complete disclosure as insensitive

- Patients were not informed about the planned treatment journey but focus was made on their current stage of treatment

- Healthcare professionals answered patients' questions without expanding

- Recommendations were made to improve awareness of available support services including psychological services, interventions to learn more from other patients' experiences and more regular contact time with healthcare professionals

At completion of treatment cycle (cycle 12 of FOLFOX or cycle 8 of XELOX)

- Patients' experiences with cancer services within the healthcare system remained overall positive
- Significant others and patients felt highly supported by nurse navigators

The day I took her to emergency, I was rather annoyed as the doctors reiterated that my mother was suffering from nothing serious... so for me this is a huge red alert! ... This must be a misdiagnosis! [daughter of patient receiving FOLFOX]

- Patients were noted to be highly sensitive to the spoken words used by healthcare professionals, stressing the need for more empathy
- Significant others expressed the patients' need for shared responsibility with the oncologist to decide what is best for the patient

I don't think it was good that they did not mention anything to us that he will be needing this treatment. We were then informed after one month at the out-patients appointment. [spouse of patient receiving XELOX]

- Recommendations were made for cancer care services to be available in the community setting, for example provision of ambulatory care, development of an outreach programme and a community palliative care programme

New services that should be introduced include provision of ambulatory chemotherapy and the setting up of an oncology outreach team ... It's good to treat patients in their home setting when it's permitted. [healthcare professional o patient receiving FOLFOX]

CONCLUSION

- **Timeliness of diagnosis and accessibility to healthcare services** were crucial in cancer care
- A "one size fits all" approach is not suitable
- **Introduction of interventions** along the treatment journey to address the patients' current needs were recommended

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D. Stewart³, A.E. Weidmann⁴

1. Robert Gordon University, Scotland

2. University of Strathclyde, Scotland

3. Qatar University, Qatar

4. University of Innsbruck, Austria

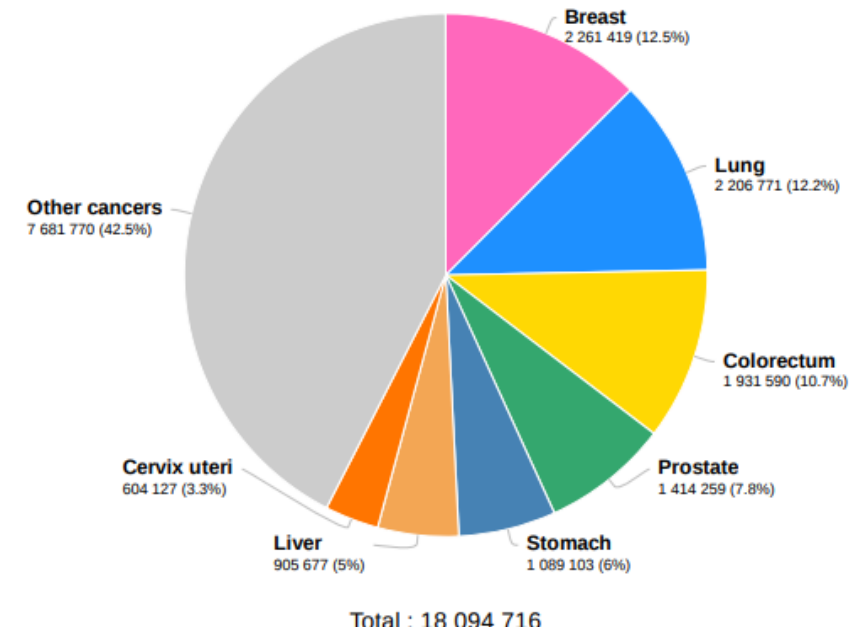


CANCER

- an international health priority
- a leading cause of morbidity and mortality worldwide
 - 18.1 million new cancer cases/year (2020) expected to ↑ by 47% in 2040
 - 10 million cancer deaths/year
- affect any individual regardless of race, socioeconomic status or geographical location
- prevalence affected by population growth and aging
- considered as chronic disease due to screening, earlier diagnosis and treatment

Sung H et al. CA: A cancer journal for clinicians. 2021; 71(3):209-249.

Johansen NJ & Saunders CM. Cureus. 2017; 9(2):e1039



Number of new cases worldwide,2020



CANCER CARE

- Increasing cancer incidence + improved survival rates = enormous stress on healthcare system
- Healthcare system experiencing an imbalance between the demand for cancer care and resource availability
- Organisation for Economic Co-operation and Development (OECD) estimated up to 20% of healthcare expenditure adds no value to recipients
- Provision of value-based, cost-effective care is a worthy goal
- To be effective, cancer care needs to:
 - involve the coordination of multidisciplinary specialties
 - be affordable, accessible, and capable of producing optimal patient outcomes

Suggestion

Shift current healthcare strategies from *volume-based* to *patient-centred care* to provide treatments which promote the best patient outcomes while driving down costs (Porter and Teisberg, 2006)

SUPPORT TO CANCER PATIENTS

- A diagnosis of cancer results in a turbulent experience for the patient
 - struggling for survival
 - increased dependence on significant others and healthcare professionals
- Support from others constitute an important part of patients' well-being
- Manage everyday problems brought about by cancer and treatment through collaborative partnership between patients and healthcare professionals, with both considered as experts of the disease
- Cancer diagnosis severely impact the lives of their families and friends



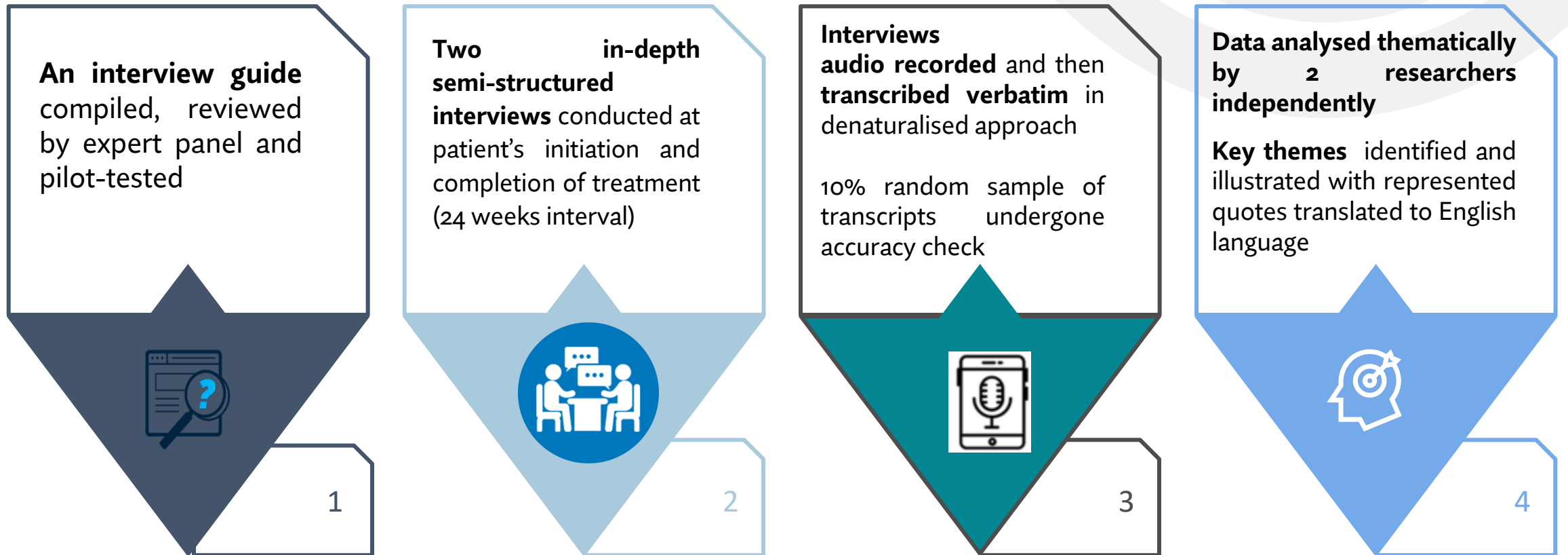
AIM



To explore the perspectives of significant others regarding cancer care experiences of patients receiving antineoplastic medicines for colorectal cancer

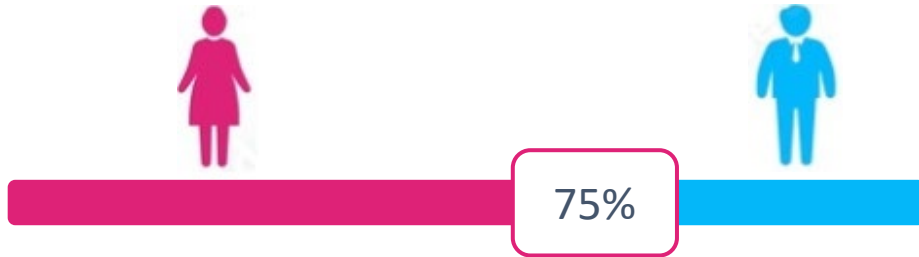
METHOD

- A longitudinal qualitative study over a 6-month period
 - Participants: 16 individuals with colorectal cancer initiating treatment with either FOLFOX for 12 cycles or XELOX for 8 cycles asked to nominate at least 1 significant other
 - Data collection period: October 2018 – March 2020
- Setting: 113-bed national oncology hospital in Malta

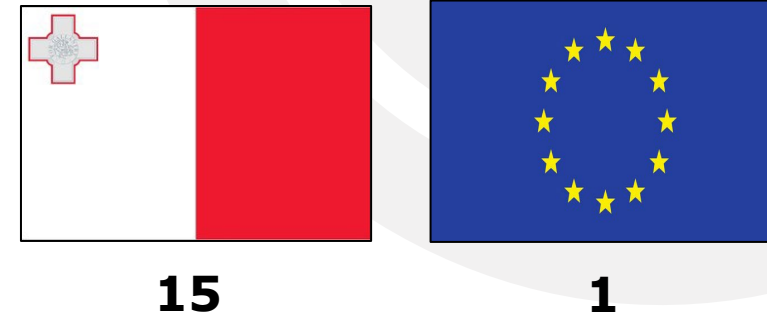


PARTICIPANTS' CHARACTERISTICS

GENDER



NATIONALITY



RELATIONSHIP TO PATIENT



- Sibling (**n=3**)
- Spouse (**n=6**)
- Offspring (**n=5**)
- Niece (**n=1**)
- Healthcare professional (**n=1**)

PATIENT'S TREATMENT



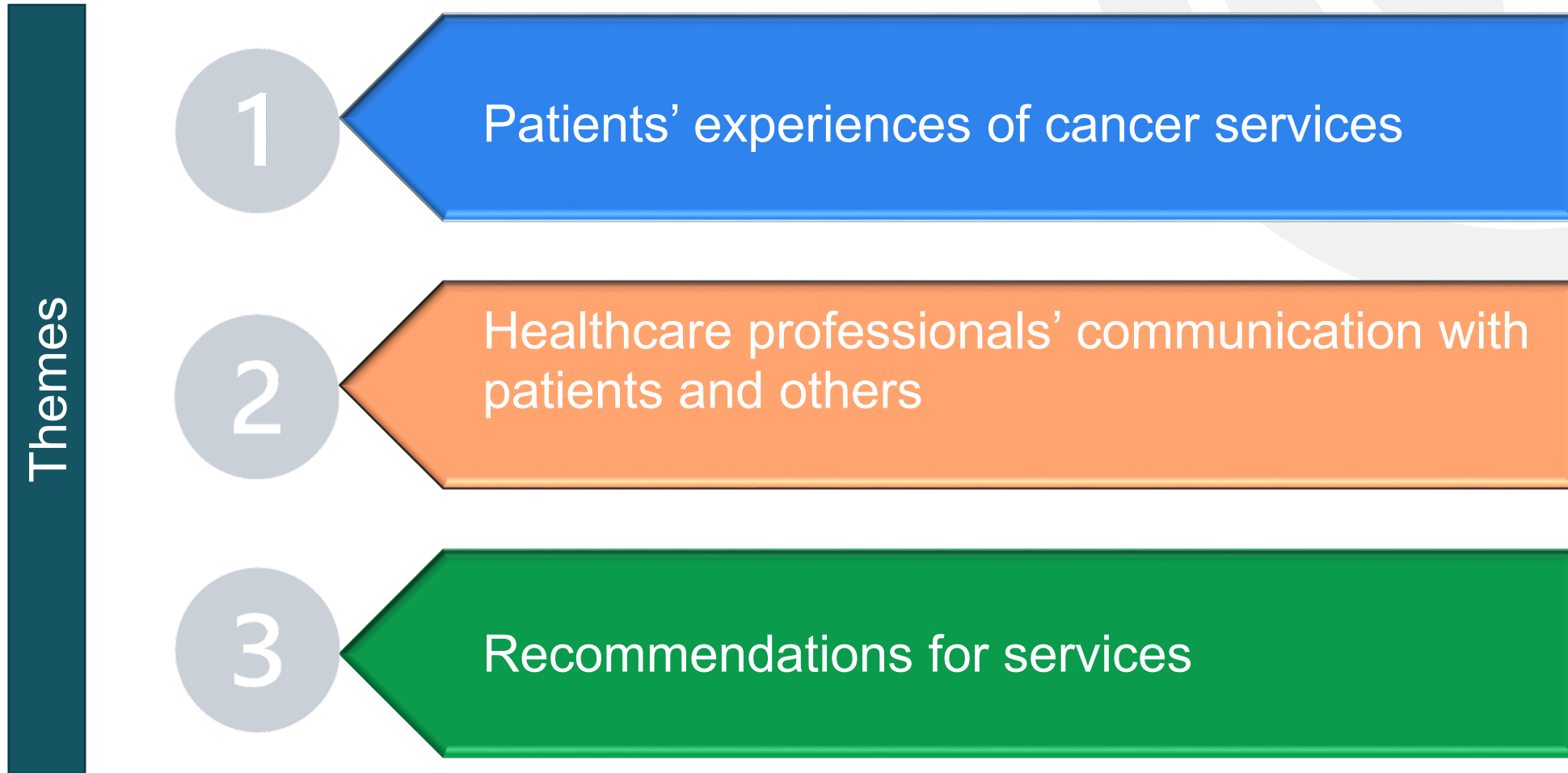
FOLFOX

Oxaliplatin
Fluorouracil
Folinic acid

XELOX

Oxaliplatin
Capecitabine

RESULTS



Theme 1

PATIENTS' EXPERIENCES OF CANCER SERVICES

*I expect that whatever has been recommended [at the information session at the oncology centre] would be followed here [oncology centre] **They advised against the use of chemicals but then why did they prescribe ... mouthwash filled with alcohol and benzene to treat her severe mouth ulcers?** ... One of my major concerns was infection. Case in point, we went to Gozo hospital for an outpatient appointment and it was overcrowded. I advised my wife to stay outside. Then I informed the nurse that my wife shall be waiting outside as she is receiving chemo.*

[S003-2 spouse of patient receiving FOLFOX]

*The day I took her to emergency, I was **rather annoyed** as the doctors reiterated that my mother was **suffering from nothing serious**... so for me this is a huge red alert! ... This must be a misdiagnosis! [S004-1 daughter of patient receiving FOLFOX]*

*The environment here is totally different from Boffa [old oncology centre] ... it was a small hospital, overcrowded ... Every time I went there, I get that unpleasant feeling of a lump in my throat. **Having the oncology centre situated next to Mater Dei Hospital [acute hospital] reduces the possibility of being labelled as a cancer patient** ... My sister feels very welcome each time she come here [oncology centre] [S011-1 sibling of patient receiving FOLFOX]*

Theme
2

HEALTHCARE PROFESSIONALS' COMMUNICATION WITH PATIENTS

When the oncologist spoke to him, he was explained that that was the only way to kill the bad cells. So he just followed advice. [S010-2 spouse of patient receiving FOLFOX]

I think she would have chosen to take treatment at home as she doesn't like to get out of her home to stay here [oncology centre] ... She would like to come here for short visits but not for 3 days at a stretch. [S006-2 – daughter of patient receiving FOLFOX]

I don't think it was good that they did not mention anything to us that he will be needing this treatment. We were then informed after one month at the out-patients appointment. [S007-1 spouse of patient receiving XELOX]

Healthcare professional should not expect the patient to ask for further information as the patient is inexperienced and maybe scared to ask for certain details. They [healthcare professionals] should be the one who provide them with the necessary details. [S014-1 daughter of patient receiving FOLFOX]

Theme
3

RECOMMENDATIONS FOR SERVICES

*New services that should be introduced include **provision of ambulatory chemotherapy and the setting up of an oncology outreach team** ... It's good to treat patients in their home setting when it's permitted ... patients suffer from effects related to chemo ... so why do they have to be admitted at Mater Dei [acute hospital] and go through the whole process of admission and many necessary tests? At some point **a symptom control unit should be set up dedicated for oncology patients** [S008-2 healthcare professional o patient receiving FOLFOX]*

*It could be beneficial that **social activities are organised for patients to meet other patients** following completion of treatment to share their experiences of how they adapted to their new routine. [S012-2 spouse of patient receiving FOLFOX]*

*I thought about the psychological effect when my husband was being informed that he is sick ... **you should speak with someone who will assess your feelings and how you're dealing with the news. But psychological help was not provided.** [S007-1 spouse of patient receiving XELOX]*

*There should be **dedicated time, particularly in the afternoon, where the consultant is available to discuss certain problems** ... without having to interrupt the medical team during the ward round for a quick conversation. [S011-1 sibling of patient receiving FOLFOX]*

*I would like to know **his assigned nurse at least for that particular day**... That way I can liaise with the assigned nurse ... the patient will also build up confidence to ask certain questions ... you know that your nurse will listen to you and don't have to repeat the same concern to different nurses. [S001-1 sibling of patient receiving FOLFOX]*

DISCUSSION

- The first longitudinal qualitative study capturing the significant others' perceptions about the patients' experiences of cancer care experiences in Malta
- Significant others were highly aware of the patient's experience with cancer and were motivated to describe such experiences

Strengths

- Study took place in the only national centre for oncology medicine in Malta
- Team of researchers with varied experience in qualitative research and familiarity with the local hospital practice
- Transparent and rigorous process followed
- Minimising recall bias as study was conducted whilst receiving treatment

Limitations

- Views only captured from participants who consented to receive antineoplastic medicines
- Translations of quotes from original language affected by richness of the language
- Caution with regard to generalisability and transferability of results to other patient groups and settings

CONCLUSION

- An **overall positive experiences** of the cancer services in Malta
 - attributed to caring and professional nature of staff, with emphasis to role of nurse navigator
 - highlighted that timeliness and accessibility to healthcare services were crucial in cancer care
 - a “one size fits all” approach is not suitable
- Identification of **areas for improvement**
 - awareness and accessibility of additional support services
 - improvement in service provided by A&E department
 - introduction of interventions along the treatment journey to address their current needs
 - provision of individual counselling using patient-tailored treatment-specific information

The patient needs an experience,
not an explanation.

— *Frieda Fromm-Reichmann* —



THANK YOU