

**EXPLORING THE INFORMATION NEEDS OF PEOPLE
WITH BLOOD CANCERS FROM A CULTURALLY AND
LINGUISTICALLY DIVERSE BACKGROUND**
A Qualitative study

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FINAL REPORT

ORGANISATIONAL DETAILS SOUTHERN HEALTH

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Executive Summary

Haematology patients receive vital information throughout their cancer journey that is important to their psychological adjustment to the diagnosis, assist in the decision making process and to ensure their safety.

At Southern Health, up to 53% of patients originate from a culturally and linguistically diverse background (CALD) posing challenges in the delivery of treatment. As healthcare professionals there is a responsibility and duty of care to ensure all information has been communicated to the patient, in their preferred language, as poor understanding, because of difficulties of language and interpretation may lead to suboptimal care.(6)

The use of professional interpreters is a requirement, as documented in the DHS Language Service Policy (2005), however increasingly phone interpreters are used for non-complex cases in the absence of on-site services. No family members should interpret as there is a breach of confidentiality, risk of misinterpretation and conflict of interest.

In this study we assessed the information needs of four patients (see table 1 for demographics), with haematological malignancies and identified a number of areas for improvement. The patients were under the care of the Haematology team in Monash Medical Centre Clayton and were receiving treatment or being reviewed in clinic and required the services of an interpreter. (See figure 1)

Semi structured interviews were conducted in a private room in clinic or the Chemotherapy Day Unit (see appendix 1). The interviews were audio taped, transcribed and organised into themes. The study used a qualitative method specifically a Phenomenological approach. This method is one of discovery and description and emphasises the understanding in the study of the lived experiences of individuals. The aim of Phenomenology is not to find significant numbers but rather themes that emerge from the narratives indicative of common human experience. Phenomenology attempts to interpret peoples' perceptions of reality often using semi-structured interviews.

The initial study findings suggest there were challenges in communication between the patients and the doctors at diagnosis with all of the patients lacking knowledge about their condition. This has been reported in a number of studies that identified the use of an interpreter service enhanced the understanding of patients from a CALD background (5)

All the patients in the study had an interpreter present at time of diagnosis and were positive about gaining information from the interpreter apart from Patient A who commented "I don't know, how do I know the interpreter is saying everything".

All the patients felt they would have benefited from the information in their language of origin as all were given the booklets in English for their English speaking relatives to translate.

The study was time limited owing to Ethical approval being declined initially. Thirteen patients were approached but only four patients participated. There was reluctance by the patients to participate and time was limited to half an hour with the interpreters, therefore a future recommendation would be to employ bilingual researchers, as suggested in several studies, to ensure the information has been delivered correctly and patients have complete understanding of the consent process.

Another recommendation would be a longer future study that could compare the information needs of the English patients as well as patients from a CALD background, as lack of knowledge may not just be limited to non-English speaking individuals.

The study identified that the information available, to individuals from a CALD background, within Southern Health was limited to some general reading material and not available in all languages. A tool, used in primary education, was identified that could assist in the delivery of information to patients from a CALD background. The Mantra Lingua pen is an inexpensive MP3 player that speaks 40 plus languages. The company provides word charts allowing anyone to design specific posters or books catering for their own needs. The pen is pointed at the chart/book and the pen then translates the information into the language you have selected.

A proposed project developing a multilingual audio guide, using the Mantra Lingua pen, is currently being implemented to assist patients from a CALD background identify their needs at time of diagnosis.

Table 1

Demographics

Number of patients: 4

Gender: 4 x Males

Preferred Language: 1x Greek, 1x Serbian, 2 x Vietnamese

Employed: 1

Retired: 3

Education: 4x School leavers

Current treatment phase: 3x receiving chemotherapy
1x Review in clinic

Introduction

With the diagnosis of cancer it has been well documented that the need for information is required for patients and family. Furthermore it is suggested that openness in communication and access to all aspects of treatment, has been found to be beneficial upon patient outcomes such as emotional well-being and enhanced coping. (1) The benefits of information for cancer patients also include increased involvement in decision making and greater satisfaction with treatment choices. (2, 3)

For patients from a non-English speaking background, there are implications when delivering all types of information about diagnosis and treatment and without appropriate translation;

” The patient who speaks no English is extremely vulnerable” (4)

Research has documented that differences in language and culture can cause breakdowns in Healthcare provider-patient communication and that when providers and patients do not share a common language, well trained professional interpreting services can achieve the best outcomes(5).

When considering the information needs of patients, from a non-English speaking background, it is clear that the cultural background of those individuals has a major impact on how the information is delivered and received.

Beliefs about cancer may differ among ethnic groups: for example Hispanic patients may believe that “it’s a punishment from God and that “destiny cannot be changed”. (7). In some Asian countries, many patients do not know what cancer is, or have misconceptions about the disease. (8, 9).

In this study we assessed the information needs of four patients (see table 1 Demographics), with haematological malignancies and identified a number of areas for improvement. The patients were under the care of the Haematology team in Monash Medical Centre Clayton and were receiving treatment or being reviewed in clinic and required the services of an interpreter. (See figure 1)

Semi structured interviews were conducted in a private room in clinic or the Chemotherapy Day Unit (see appendix 1). The interviews were audio taped, transcribed and organised into themes. The study used a qualitative method specifically a Phenomenological approach. This method is one of discovery and description and emphasises the understanding in the study of the lived experiences of individuals. The aim of Phenomenology is not to find significant numbers but rather themes that emerge from the narratives indicative of common human experience. Phenomenology attempts to interpret peoples' perceptions of reality often using semi-structured interviews.

Project methodology

Participants: Initially thirteen patients were approached to participate in the study (see figure 1) however only **four** Haematology Patients with malignancies, from a culturally and linguistically diverse background (CALD) consented to participate in the study all of whom required the services of an interpreter. Two of the participants were recruited in Haematology clinic at Monash Medical Centre Moorabin during their regular clinic review and two in the Chemotherapy Day Unit. With an Interpreter present the research coordinator guided the participants through the patient information and consent form and then the participants were given the opportunity to ask questions. Whether recruitment took place on the Chemotherapy Day Unit or the clinic at Moorabbin, the participants were given the protocol and patient information sheet, in English, to discuss the study with their English speaking family. The Research Co-ordinator rang the relative a week later to determine if the patient was interested in participating and then organised a date to meet with the patient and interpreter to undertake the interview.

Materials: All interviews were recorded using a digital device. The recordings were then transcribed onto a computer database.

Design: The study used a qualitative method specifically a Phenomenological approach. This method is one of discovery and description and emphasises the understanding in the study of the lived experiences of individuals. The aim of Phenomenology is not to find significant numbers but rather themes that emerge from the narratives indicative of common human experience. Phenomenology attempts to interpret peoples' perceptions of reality often using semi-structured interviews.

Procedure: All participants were interviewed in one single session, for approximately half an hour, with an independent interpreter present at all time. The interviews took place in a private room in the clinical area of the Chemotherapy Day Unit or the clinic. The areas were chosen as participants could be interviewed during their treatment, or review with the doctor, and thus minimise any inconvenience to them. Each interview was audio taped and the investigator explained that she was there to learn about the information they had received during their cancer journey and how that affected their feelings towards their illness and treatment. (see appendix 1)The interviews were semi-structured but flexible depending on the participants' responses. Each interview continued until no new information was forthcoming or participants became fatigued. Each interview was transcribed identifying every response, Words, phrases and sentences were coded to determine what was being said. Words were coded for meaning and themes then emerged from the codes.

Findings & Discussion

Lack of information and communication breakdown were central themes that emerged, from diagnosis through to treatment, with all the participants demonstrating emotions ranging from anger through to general acceptance of the healthcare system, despite having a lack of knowledge.

Information at diagnosis

Lack of knowledge at diagnosis despite the presence of an interpreter appeared to be a common issue among a couple of the participants that led to challenges in communication with their physician.(see table 2)

Table 2

Lack of information and knowledge at diagnosis

“Doctors don’t care if the patient understands”

“Doctors holding back information”

“I don’t know the cause the doctor did not explain it to me”

“He was not sure about the diagnosis; the doctor did not explain where the illness came, it was a long time ago”

“Yes there was an interpreter present and I felt respected by the doctor”

“I think doctors explain information well now, better than 10 years ago. Treatment of patients has improved”

At diagnosis patients are vulnerable and therefore the delivery of information has to be sensitive especially via an interpreter. As stated in a study by Pascal et al (10)

“The cancer diagnosis and treatment process often result in increased levels of psychosocial apprehension, anger, fear and confusion for patients and their families. This state of psychological disequilibrium could be aggravated by hurried interactions between the patient and the Oncology professionals”.

One of the participants felt the physician was holding back information and this led to distrust in the relationship between patient and the doctor. The participant felt the doctor did not care if he understood the information or not. Consequently the participant felt disrespected because he did not speak English.

One of the participants did not understand the cause of his disease but was accepting of the service he had been provided and did not wish to challenge the system. Two participants were satisfied with the information they had been given at the time of diagnosis.

Communication breakdown with individuals from a CALD background

Difficulties in communication breakdown with the healthcare team were key issues with two participants. (See table 3). Despite the requirement of an interpreter the participants had acquired a small vocabulary of English words that gave them the ability to have some understanding of the English speaking Healthcare workers.

Table 3

Healthcare professionals limited knowledge of participants understanding

“Village people have a better understanding than professionals think”

“You feel like shot knife into your heart, you don’t get the attention you should”

“Introduction and name of professional instead of waiting for

One participant believed that the assumption of the healthcare workers that he did not understand their conversation allowed them to discuss private issues unrelated to his care; “Introduction and name of professional instead of waiting for them to talk about their private lives” The lack of knowledge of the healthcare workers led to communication missteps that resulted in the participant having a diminished feeling of respect and dignity; “You feel like shot knife into your heart, you don’t get the attention you should” .Another participant believed HealthCare workers assumed he originated from a lower socio economic group due to his inability to communicate in English effectively; “Village people have a better understanding than professionals think”. This participant perceived there was a lack of respect owing to his inability to communicate.

Information received during treatment

All participants had received written information in English but all stated the importance of receiving Information in their language of origin.(see table 4)

Table 4

Information in language of origin

“No Serbian information”

“Of course it would have been beneficial to have the information in Vietnamese”

“Of course it would have been better to have the information in Greek”

It is well documented that cancer patients desire as much information as possible. Written information can be read repeatedly, assimilated and processed over the course of treatment. Iconomou et al (11) identified that the provision of well-structured and adequate information about cancer treatments is greatly appreciated by patients and exerts beneficial effects on a number of outcomes. Each participant had been given information in English but they were all reliant on the interpreter or family members to translate the text. They all expressed a feeling of self-worth if they were able to read the information themselves.

Lifestyle information

One participant believed information did not just have to be about side effects but also lifestyle changes.(see table 5)

Table 5

Lifestyle information

“Didn’t tell me how to live”

“Don’t tell you about lifestyle”

“It would help to have support of a specialist as to how to live your life”

A study identifying patient perceptions of quality of care by race, ethnicity and language highlighted (12) half the patients reported insufficient information regarding lifestyle changes for example relationships with their spouse/partner and work. The participant believed that individuals could maintain a healthy lifestyle but was frustrated and felt that; "It would help to have the support of a specialist as to how to live your life"

Knowledge gained through an interpreter

All participants had been seen at diagnosis with an interpreter present. (See table 6)

Table 6

Perceptions of the interpreting service

"Yes interpreter sometime, sometime interpreter sometime not"

"Yes the interpreter explained everything to me while I was having Treatment"

"Yes the interpreter knows the jargon so they are able to Understand everything"

"I am not sure I don't know if the interpreter is saying everything"

"Maybe I am not sure I think it is better through the interpreter But I feel better with my family"

Two of the participants believed the outcomes with interpreters were positive however one participant expressed concern; "I am not sure I don't know if the interpreter is saying everything". A recent study by Butow et al(13) highlighted this issue and identified that even with access to the interpreting service, information may be altered. It was also suggested that with an interpreter everything was required to be repeated twice, thus owing to the fixed time for consultation, patients from a CALD background may consequently receive less information. This was supported by another study by Aranguri et al(14) who identified the presence of an interpreter increases the difficulty of achieving good physician /patient communication,

Another study by Leah et al (5) contradicted this theory by suggesting;

"That the use of professional interpreters is associated with improved quality of healthcare for patients with limited English proficiency and that the use of professional interpreters is associated with a positive impact that is greater than that of ad hoc interpreters"

The study was time limited owing to Ethical approval being declined initially. Thirteen patients were approached but only four patients participated. There appeared to be reluctance on the patients' part citing a number of reasons why not to participate, and the added complication was, time was limited to half an hour with the interpreters. This proved difficult for the principal researcher to spend sufficient time with the potential participants. There are a number of studies that have identified the issue of minority groups taking part in research

In a study by Corbie-Smith et al (15) they had identified distrust in the African American population in participating in research with a number of responses indicating that the candidates believed they would be asked to participate in harmful research.

Next steps / conclusion / recommendations

The aim of the study was to explore the information needs of people with blood cancers from a culturally and linguistically diverse background and identify if those needs were being met.

The findings clearly demonstrate there were deficits in knowledge, among this group of participants, but also evidence of communication breakdown despite the use of the interpreting services.

1. Lack of knowledge at diagnosis led to breakdown in communication and thus impacted on the patient/physician relationship.
2. Lack of knowledge of healthcare workers, in relation to the participants understanding of a few English words, led to communication missteps that were perceived by the participants as a lack of respect.
3. Lack of information in the language of origin was noted by all the participants with one participant requiring further information about lifestyle.
4. Despite having access to the interpreting services, one participant was concerned that the interpreter may not be translating the correct information.

In accordance with previous research the care of for patients from a CALD background remains a challenge .Overcoming cultural, social and linguistic barriers may lead to improved care and positive encounters with the patients and their families.

Recommendations

1. A number of studies have recommended a communication workshop for physicians and interpreters that would enhance the consultation and ensure the correct information is delivered to patients from a CALD background. One article (13) suggested increasing the length of consultation time for patients from a CALD background to give them the opportunity to develop trust with their physician.

2. Cultural awareness workshops for all healthcare workers to improve communication between the patients from a CALD background.

3. The study identified that the information available, to individuals from a CALD background, within Southern Health was limited to some general reading material and not available in all languages. A tool, used in primary education, was identified that could assist in the delivery of information to patients from a CALD background. The Mantra Lingua pen is an inexpensive MP3 player that speaks 40 plus languages. The company provides word charts allowing anyone to design specific posters or books catering for their own needs. The pen is pointed at the chart/book and the pen then translates the information into the language you have selected.

A proposed project developing a multilingual audio guide, using the Mantra Lingua pen, is currently being implemented to assist patients form a CALD background identify their needs at time of diagnosis.

4. The study was time limited owing to Ethical approval being declined initially. Thirteen patients were approached but only four patients participated. There was reluctance by the patients to participate and time was limited to half an hour with the interpreters, therefore a future recommendation would be to employ bilingual researchers, as suggested in several studies, to ensure the information has been delivered correctly and patients have complete understanding of the consent process.

5. Another recommendation would be a longer future study that could compare the information needs of the English patients as well as patients from a CALD background, as lack of knowledge may not just be limited to non-English speaking individuals.

6. Implementation of interventions required to address the issues raised by this research project is beyond the scope of this study. Such research would require significant resources, and will likely take form in a subsequent project for the future at Southern Health.

Appendices

Appendix 1

Open ended questions to be used by the Research Co-ordinator in a semi structured interview for individuals with blood cancers from a culturally and linguistically diverse background.

Age: Preferred Language spoken:
Country of Birth:

Gender: Date commenced treatment:

Current treatment phase:

Education: School only:
Further Education:
University Education:

Employed:
Unemployed:

Could you tell me, in detail, your understanding of your illness?

Could you describe, in detail, how you felt when the doctor first talked to you
About your illness?

What is your understanding of what will happen in the future?

Could you describe, in detail, the type of information you have received about you illness?

Is there any particular aspect of the information you received that you did not understand?

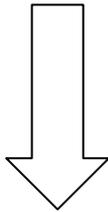
Were you satisfied with the information you received and if so how?

Could you describe what changes, you feel, should be made to improve your experience
as a patient or is there anything else you would like to tell me?

PARTICIPANT RECRUITMENT TO THE STUDY

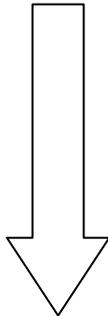
Figure 1

13 PATIENTS IDENTIFIED FOR RECRUITMENT TO THE STUDY.



13 POTENTIAL PARTICIPANTS APPROACHED IN HAEMATOLOGY CLINIC AND ON THE CHEMOTHERAPY DAY UNIT. INTERPRETER PRESENT FOR INITIAL DISCUSSION. PATIENTS GIVEN THE INFORMATION SHEET IN ENGLISH AND TWO WEEKS TO CONSIDER THE OPTION OF PARTICIPATING. PRINCIPAL INVESTIGATOR THEN CONTACTED ENGLISH SPEAKING RELATIVE TO DETERMINE THEIR INTEREST

9 declined consent



3x stress	2x poor memory	3 x happy with service	1x did not meet criteria
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4 PATIENTS RECRUITED TO THE STUDY

Abbreviations

(List them all here)

CALD	Culturally and linguistically Diverse
DHS	Department of Human Services
SMICS	Southern Melbourne Integrated Cancer Service

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