"They don't give us the full story"

Attitudes to Hospitalisation Amongst

Yolŋu People of North-East Arnhem Land

- A Comparative Study.

Howard Amery

August 1999.

Funded by Territory Health Services 1998-99

Implemented by Aboriginal Resource and Development Services Inc.

Acknowledgements

To the many Yolŋu* people who participated in this project and shared their experiences, stories and reflections - this is your collective story. Your honesty and frankness in the way you shared about some aspects of your hospital experience will hopefully be of assistance to many non-Aboriginal people in learning about the special needs of Yolŋu and other Aboriginal people within the hospital environment.

I am indebted to my colleagues Gillian Campbell, Richard Trudgen, Bryan Macdonald and Dale Chesson for their assistance in conducting the research and in proof-reading the drafts of this report.

Special thanks to the THS Project Advisory Committee and especially to Peter Lindenmayer for his unstinting support, helpful insights and many useful comments made during the write-up of the research project.

Thanks also to Sue Ibbs (Librarian THS East Arnhem) for assisting in locating relevant reports and for her diligence in obtaining them.

* see Glossary of Key Terms - Appendix 1

CONTENTS

Executive Summary

The attitudes of Yolŋu persons towards their recent hospitalisation experiences (i.e. 1995-99) at Gove District Hospital (GDH) were obtained through the conduct of community-based interviews and the results compared with attitudes obtained from interviews of current patients. A Project Reference Group from THS provided support and oversight for the research project.

The study identifies a number of themes arising from the responses of ex-patients, primarily around the issue of communication difficulties experienced and more specifically with their lack of satisfaction with explanations given concerning diagnosis and treatment. A number of sub-themes arising from these profound communication difficulties and the different ontological frames of reference which Yolŋu adhere to are explored, namely :

- "Doctors are hiding something"
- "If they don't get enough story they will straightaway think 'galka'"
- "I went to see the marrŋgitj"
- "I believe God that he healed me"
- "They should say the names of all the different medicines, how they will work"
- "I didn't ask the doctor any questions…."
- "Sometimes the English is hard"

The role of escorts, staff understanding of the cross-cultural aspects of provision of appropriate patient care, the absence of interpreters and the fear that Yolŋu have of the 'foreign' hospital environment, are also explored.

The report identifies an acknowledgement by Yolŋu of some positive changes that have occurred, specifically in relation to staff attitudes over the past 10 or more years and in the level of satisfaction with the standard of care currently experienced.

A major finding arising from the research is the failure of the hospital system to provide for the basic communication needs of Yolŋu and Aboriginal people in general (as per the THS Patient Charter, p 12) "to be given a clear explanation of proposed treatment, including material risks and alternative medical treatment"; and the critical need for the provision of language services for all Aboriginal patients who possess 'minimal' or 'conversational' English skills.

A number of the recommendations contained within the report arise specifically in reference to those communication needs.

Recommendations

1. The provision of a Language Services Team at GDH to facilitate the communication and education needs of Yolŋu patients. (In addition to the presence of several Yolŋu persons to function in the roles of hospital liaison and trainee interpreter / educator, this team would also need to incorporate the services of an English-first-language health educator. The educator would need to possess Yolŋu-Matha skills sufficient to enable them to work in a dynamic team relationship with several Yolŋu co-workers.)

2. That an escort accompany all elderly patients (i.e. those over 60 yrs).

3. That the current policy / practice for escorts to accompany all first-time and teenage antenatal patients when sent in to await confinement be continued.

4. That, while awaiting the provision of formal communication / language services by THS, the expectations of THS staff concerning the role of escorts be revised to incorporate a realistic assessment of the language difficulties commonly faced by both patients and escorts.

5. Attendance at Cultural Awareness Workshops run in the East Arnhem region be compulsory for all medical staff, whether short term or longer term employees, for all nurses employed for more than 3 months and for all other longer term staff.

6. Negotiate with appropriate agencies and cross-cultural training providers for the provision of additional 'health-issues' and skills-based communication workshops, for staff who have already attended an initial Cultural Awareness workshop relevant to the East Arnhem region.

7. A variety of cassette tapes of christian music (all recorded in Yolŋu Matha) be purchased by THS to be played in the ward at suitable times. THS to contact Bible Translation Centre at Galiwin'ku to negotiate that supply.

8. That THS explore strategies to enable the conduct of shopping or banking trips for patients who are physically unable to do so, or for those who are intimidated by the presence of 'drunks'.

1. INTRODUCTION

A Patient Satisfaction Survey conducted at Gove District Hospital (GDH) in 1997 interviewed a total of 45 hospital-based Aboriginal persons, 29 of whom were Yolŋu Matha* speakers. The results of this survey are summarised in Appendix 2. THS proposed a follow-up survey of the attitudes of ex-patients of GDH, in an effort to better understand Aboriginal patients' experience and expectations of hospitalisation and to see what effect time away from hospital and being interviewed in the context of one's own home surroundings and language may have in relation to the level of satisfaction felt about the standard of treatment received by patients while in hospital.

ARDS' experience of working with Yolŋu communities, and the perceived advantages of conducting these unstructured interviews in a Yolŋu language and by persons who are reasonably familiar in most Yolŋu communities, formed the basis for THS again approaching ARDS to conduct this research.

* see Glossary

2. LITERATURE REVIEW

2.1 Indigenous Australians & Hospitalisation

The attitudes of indigenous Australians to hospitalisation has been a small, but essential part of the health literature since Byrnes and Ward (1977) first wrote concerning problems typically encountered by Aboriginal children while hospitalised. While much of the research conducted to date has non-traditional Aboriginal populations as its focus, a number of important themes emerge which have either informed, or are of relevance to, the delivery of mainstream hospital services in those regions or specific locations where Aboriginal in-patients predominate. Eckermann et.al. (1992, p 200) identifies a 'cycle of culture shock' which Aboriginal patients typically experience that is marked by "fear, isolation, withdrawal, dependency, depression and powerlessness".

2.1.1 Communication : This is identified by Eckermann et.al. (1992, p 173) as a primary stressor for Aboriginal patients, even in those contexts where English was commonly spoken, with medical staff commonly experiencing "difficulty communicating" …. and Aboriginal patients having "real difficulty explaining to / understanding medical staff". Difficulties in communication are widely reported and involves a large complex of behaviours, both verbal and non-verbal. Knowledge of cultural conventions, perspectives, customs and etiquette are all recognised as factors which can either aid or detract from the conduct of effective communication and this is observed to work 'both ways' (Devitt and McMasters 1998, p 147) between medical staff and Aboriginal patients.

2.1.2 Foreign/Alien Environment :

Within the literature, the 'foreign', 'alien' and 'frightening' nature of hospitals is well documented (Byrnes and Ward 1977; Paul 1999; Reid and Dhamarrandji 1978; Eckermann et.al. 1992, Carter and Bartlett 1991). Hospitals are seen by many Aboriginal patients as unfriendly and impersonal places where foreign language and foreign culture predominate and where care is offered "in isolation from the context of people's lives" (Paul 1999, p 15). The absence of Aboriginal staff within the hospital or treatment centre context contributes to this perception of foreignness and is commented on in several studies (Reid and Dhamarrandji 1978; Kildea 1999). Commonly, there was a lack of Aboriginal persons employed as doctors and nurses or even as health workers (Taylor 1997; Muir 1999) and few as ancillary hospital staff. Also, interpreters of any sort were observed to be largely absent. Support provided to the few Aboriginal workers employed is generally regarded as insufficient (Taylor 1997; Muir 1999).

Studies of the attitudes of traditional (i.e. non-urban) Aboriginal patients within mainstream health settings are generally more recent and tend to focus on more select populations such as renal patients (Devitt and McMasters 1998) or birthing women (Watson 1987, Fitzpatrick 1995, Kildea

1999). Again a number of important themes arise, but issues of particular significance are those concerned with language and communication, and the way that mainstream services are either impaired or have been adapted in order to overcome some of the multiple barriers that exist when English is not the first or everyday language of the patient. Several issues arise from these general language / communication problems :

2.1.3 A perceived reluctance to explain treatments and diagnoses to Aboriginal patients. Reid & Dhamarrandji (1978) in particular suggest that Yolŋu feel information is deliberately withheld from them by doctors and hospital staff because of their Aboriginality. Mistrust of medical procedures, medicines and hospital staff intentions are observed to be more pronounced when communication is poor. Similarly Devitt and McMasters (1998, p 168) found "the overwhelming majority of patients had little bio-medical understanding of either their illness or their treatment".

2.1.4 Interpreters - A lack of interpreters, trained or otherwise, is the predominant finding from other studies. Aboriginal people in at least two studies suggested that communication could be greatly improved if interpreters were used. (Reid and Dhamarrandji 1978; Devitt and McMasters 1998).

2.1.5 Fear. Writing about Aboriginal maternity patients of traditional origin in the context of their hospitalisation at RDH, Watson (1987, p 42) says "The attitude of Aboriginal people towards hospitalisation and western medical practice can be summed up in one word, 'fear' ". Fear of dying, of being examined / touched by strangers, of blood tests, x-rays, machines and medical procedures are well documented. (Watson 1987; Reid and Dhamarrandji 1978; Eckermann et.al. 1992; Kildea 1999).
Additionally, because Aboriginal patients traditionally see sickness as a result of 'disturbed relationships' or due to 'violation of law', sorcery often looms as a possible / plausible explanation for its cause (Devitt and McMasters 1998; Reid and Dhamarrandji 1978; Watson 1987). As a result, the diagnosing and healing powers of a traditional specialist-healer are seen by many Aboriginal patients as essential in not only dealing with their fear of sorcery, but also in assisting with their recovery. Attitudes towards and acceptance by hospital medical staff of traditional Aboriginal medical beliefs and knowledge is an additional factor commented on in the literature. If traditional explanations of causality are listened to and seen as potentially complementary (Reid and Dhamarrandji 1978), then additional opportunities exist for alleviation of fears, better communication, mutual sharing of ideas, compliance and therefore, for healing and recovery.

2.1.6 Escorts - Several studies make mention of an "Aboriginal cultural imperative" for appropriate kin to accompany sick relations to hospital (Coulehan 1996; Reid and Dhamarrandji 1978; Kildea 1999; Devitt and McMasters 1998). Feelings of loneliness, despair and sadness are alleviated to

a large degree when one or several family members are allowed to comply with culturally-patterned requirements and 'keep company' with the sick relative. Escorts were also observed to be essential in support of young maternity patients. Some changes in policy in THS 'PATS' procedures since Reid and Dhamarrandji's study (1975) are also noted, such that those under 16 years of age are now automatically entitled to an escort.

2.2 Comparable Studies

No comparable studies of attitudes specific to hospitalisation experiences are known to the researchers. Research conducted by Janice Reid at Yirrkala in 1974 detailed four case studies, in which the patient absconded from hospital, as 'typical' of problems often encountered at GDH. Her study provides perhaps the closest insight and parallel study to those conducted by ARDS (1997) and the current study.

2.3 Methodological Issues

Devitt and McMasters (1998), Senior (1999), Reid and Dhamarrandji (1978), Fitzpatrick (1995) and Watson (1987) all make use of unstructured qualitative face-to-face interviews in surveying the perceptions or attitudes of Aboriginal patients / clients. The question of subjectivity versus objectivity within the cross-cultural, multi-lingual research environment is extensively discussed by Devitt and McMasters (1998) and also by Kemp (1998). Relationship with interviewees, knowledge of their social realities, the use of an Aboriginal language for conduct of interviews and 'data triangulation' are all seen as helpful components in obtaining data which is capable of accurately articulating the points of view of Aboriginal patients.

3. METHODOLOGY

3.1 Survey Parameters

A Project Advisory Committee was formed by THS to work with ARDS in planning the general parameters for the survey population and devising general guidelines detailing 'where', 'when' and 'how' interviews would be conducted. Yolŋu adults previously hospitalised at GDH within the past 5 years and resident in the North-East Arnhem communities of Ramingining, Galiwin'ku, Yirrkala and Gapuwiyak were chosen as the target group for the study. These will be referred to throughout the course of this document as GROUP A. In addition, a smaller 'comparison' group of in-patients from GDH were chosen to provide a point of reference in ascertaining the significance of patient reflections 'after the event' and of a changed location for the conduct of interviews. This group are referred to as GROUP B.

A separate interviewing proforma for the purposes of note-taking was drawn up in consultation with THS for each of the hospital-based and community-based survey populations. Interviews were conducted from 21/4/99 – 9/6/99.

3.2 Interviewers

A total of three persons (2 male and 1 female), were used to conduct interviews in four separate community / home locations. Each of the interviewers has a history of several years employment in at least one North-East Arnhem community, a close association of 10 or more years working with a variety of communities, clans and families across the North-East Arnhem region and knowledge of the relevant social histories, linguistic identities and cultural perspectives of Yolŋu people in general. Although not formally qualified as interpreters, all interviewers currently work as community educators and regularly use 'Yolŋu Matha' as an integral part of the health intervention and other education programs that are conducted by ARDS Inc. in North-East Arnhem Land communities.

Many of the persons contacted for interview were therefore either directly known to the interviewer or able to be easily placed within the clan-based social fabric of kin and 'known' persons, such that few could be accurately regarded as strangers to the interviewer. While this latter feature is purposely omitted from the conduct of most research in the interests of maintaining 'objectivity', the cross-cultural and linguistic context of this particular research project suggests that 'familiarity' and 'relationship with' provides a number of advantages which are able to far outweigh the disadvantages that such relationship and pre-existing knowledge may incur (Kemp 1998).

3.3 Establishing the Context for the Interview

This proved to be the most time-consuming and challenging part of the research, and in quite a number of cases numerous contacts had to be made before a successful sit-down interview was able to proceed. Being reasonably familiar with the everyday run of events in the chosen community locations, the interviewers did not approach the task from the viewpoint of seeing

Yolŋu as persons with nothing better to do than talk to a Balanda* researcher about their own private 'health' business. For this reason it proved highly advantageous for interviews to proceed in those contexts where the interviewing agent was already a known entity. This was especially so when interviewing ex-patients within their own 'home' environment.

GROUP A (comprising 41 ex-patients) – Letters were initially written by THS to each of the community councils in the communities selected for the survey as a matter of courtesy. This was then followed by a subsequent visit or visits by the interviewer to the particular community to make direct contact with likely Yolŋu interviewees. A range of screening strategies and methods of approach for contacting likely interviewees were utilised, largely dependant on the degree of familiarity of the interviewer with the selected person or persons. This was necessary in order to ascertain whether or not the person contacted would agree to being interviewed, or indeed whether they might be able to suggest a member of their immediate family or a close relation who might be willing to be interviewed.

Once a prospective interviewee had been contacted, all conversations proceeded from the context, interests and perspectives of 'where each person was at'. Often a significant period of time elapsed (sometimes as much as 15-20 mins) before the interviewer felt free to ask about their recent history of medical-related travel and discover whether or not an interview could proceed. Other times, a relatively brief conversation (2-5 mins) ensued during which time it was quickly determined whether or not the person fitted the category of 'interviewee'.

The next phase, that of gaining the person's 'informed' consent in order for the interview to proceed, either immediately, or at a subsequent but mutually agreed time, also proved in a number of instances to be equally challenging. Most Yolŋu are not particularly familiar with Balanda concepts such as 'surveys', 'data', 'interviews', 'research report' etc. Quite a deal of time was therefore spent in establishing the overall *context* of the interview (i.e. why it was important for Yolŋu ex-patients to talk about certain aspects of their recent health encounters, while a 'researcher' listens to and then writes down the story and certain other information on to a piece of paper ……. and then to visualise where this document will end up and what impact or implications it might have). This is especially so when many of these concepts are not part of people's experience and have not as yet been linguistically analysed sufficient for Yolŋu language terms to have been 'coined' to accurately convey the particular concept. As the initial part of the survey was in all cases conducted by the interviewer in Yolŋu Matha*, this often involved a fairly lengthy explanation so that the context for conduct of the subsequent interview was clear, without resorting to 'foreign' English words to establish the particular 'foreign' concept, and the overall 'foreign' context.

* see Glossary

GROUP B (comprising 10 hospitalised persons) – By comparison, this group proved relatively easy to contact by virtue of their being 'captive' within the confines of GDH. The focal issue became the need to obtain the 'informed' consent of each patient, in order for the interview to proceed, and so was approached in the same manner as with Group A interviews.

3.4 The Interview

The aim of the interview was to establish a climate of trust, comfort and confidence between interviewer and interviewee so that the latter felt able to share with the interviewer about their hospitalisation experience/s. A narrative approach was encouraged by the interviewer so that the person talked and shared about the things they wanted to talk about in the style and way that they preferred. Towards the end of the interview, specific questions were sometimes asked in order to obtain a degree of comparability and consistency in relation to the interviewee's responses.

Most interviews were conducted either in Yolŋu Matha, or a combination of Yolŋu Matha and some English. An assessment concerning the degree of English proficiency of the interviewee was made fairly quickly by the interviewer on the basis of prior conversations, as well as observations made about the degree of comfort displayed by the respondent in their use of English language. This was especially evident when persons were asked to nominate the number and length of previous visits to hospital and also their age in years, which for Yolŋu are foreign constructs and consequently often difficult for them to describe. Before termination of the interview participants were rated by the interviewer on a scale of 1 – 5, according to their English competency.

1	2	3	4	5
Minimal	Conversational	Satisfactory	Good	Excellent

(A more complete definition of these categories is found in Section 4.1.3 English Proficiency).

Persons of Proficiency 1 & 2 responded to the interviewer's Yolŋu Matha conversation style almost entirely in Yolŋu Matha. Several persons with Proficiency 3 gave up to half of their responses in English according to the matters under discussion. Persons with Proficiency 4 rating felt comfortable using either English or Yolŋu Matha, but tended to use Yolŋu Matha for more conversational or narrative aspects and English for the more specific or quantifiable aspects of their hospitalisation experience. A number of these interviews were conducted predominantly in English.

4. SURVEY GROUP PROFILE

In Group A a total of 41 ex-patients were interviewed in five separate community locations and in Group B a total of 10 in-patients were interviewed at GDH.

4.1 Communities Surveyed – Group A

In all, a total of 18 different clan groups were represented in the sample of 41 interviews conducted in separate community locations.
(As only one person from Gunyaŋara was interviewed, she has been grouped with the other respondents from Yirrkala because of the close proximity and high mobility and contact between these two communities).

Community	**Female**	**Male**	**Total**	**No of clans surveyed**
Galiwin'ku	6	7	13	8
Gapuwiyak	2	3	5	5
Ramingining	8	8	16	7
Yirrkala / Gunyaŋara	7	-	7	5
	23	**18**	**41**	

4.1.1 Gender and Age

A fairly even gender mix of respondents was obtained. Older persons were over-represented in terms of their numbers within the wider community population, but as they constitute a significant proportion of hospital admissions, this was not perceived as a difficulty.

Age Cohort	**Female**	**Male**	**Total**
15-19	1	-	1
20-24	-	-	-
25-29	1	1	2
30-34	3	2	5
35-39	5	1	6
40-44	3	2	5
45-49	3	3	6
50-54	1	1	2
55-59	2	1	3
60-64	2	5	7
65-69	2	2	4
Total	**23**	**18**	**41**

More females than males were interviewed from the 'under 40' age group (a ratio of 10 : 4). A sizeable number of young men were approached for interviews, but for many of them hospitalisation was not found to be part of their recent experience. Due to their higher frequency of attendance at hospital for reasons of 'birthing' and 'mothering responsibilities', a greater number of younger females were able to be interviewed.

4.1.2 Reason for Hospitalisation

Of those surveyed, a wide variety of reasons were found for their admission to hospital and these are summarised below. The numbers of those admitted for maternity reasons within the survey group is significantly lower than is commonly found in the hospital population.

Reason	**Number of Patients**	**Knows Interviewer**
Escort	7	7
Operation	5	4
Heart	5	5
Asthma	4	4
Pain	3	3
Pneumonia	3	3
X-ray	2	2
Boil	2	2
Maternity	1	1
other	9	8
Total	**41**	**39**

Almost all persons interviewed either knew the interviewer personally, or were familiar with the interviewer and/or their employer organisation (ARDS Inc.). However participants were not always known to the interviewer(s) and several interviews were conducted as a result of the interviewer being called over to a person's house for a casual conversation, which later ended with that person's agreement for an interview to be conducted.

Several interviews were planned to take place with women who were well known to the male interviewer and whose reason for hospitalisation was likely to be maternity. Most of these interviews did not take place however, either because of non-attendance at a subsequently agreed appointment, or by 'polite refusal'. The reluctance by some Yolŋu women to discuss their hospitalisation experiences, is most likely gender-related, reflecting their reluctance to discuss medical relating to 'women's business' with a male person.

4.1.3 English Proficiency

English is for most Yolŋu a foreign language which they are able to use with varying degrees of competence within the foreign cultural contexts of health, education, local government and legal services provision. Yolŋu encounter most of these contexts on a regular / frequent basis. Consequently, English competence was anticipated by the researchers and Project Advisory Committee to be significant in terms of establishing the degree of satisfaction reported by patients over a range of issues within the 'foreign' hospital environment. It was therefore vital that the level of English Proficiency be assessed and documented and so the following rating scale was used by each interviewer to assess this competency for each person interviewed.

> **1 - Minimal English** (comprehends and speaks a minimal amount of English, but with difficulty).
> **2 – Conversational English** (comprehends everyday conversational English and is able to make oneself understood in general conversation).
> **3 – Satisfactory level of English** (has adequate skills to conduct a meaningful, free-flowing conversation - comprehends a minimal amount of abstract and technical English terms).
> **4 – Good English** (good fluency in everyday conversation and a range of idiomatic language, but limited comprehension of most English technical terms and many abstract concepts).
> **5 – Excellent English** (comprehension and speaking skills to the standard of an average native adult English speaker).

Age Cohort	**Eng Prof 1**	**Eng Prof 2**	**Eng Prof 3**	**Eng Prof 4**	**5**	**Total**
15-19				1		**1**
20-24						**-**
25-29	1	1				**2**
30-34		3		2		**5**
35-39			1	5		**6**
40-44			2	3		**5**
45-49		1	3	2		**6**
50-54		1	1			**2**
55-59		2	1			**3**
60-64	3	3	1			**7**
65-69	3		1			**4**
Total	**7**	**11**	**10**	**13**	**0**	**41**

It is interesting to note the clustering of good English proficiency in the 35-49 age cohorts (Prof 4 = 77% and Prof 3 = 60%, compared to Prof 2 = 9% and Prof 1 = 0 %), which reflects the hiatus era of 'mission schooling' and subsequent 'secondary college' education received in East Arnhem communities. Even though the survey population is admittedly quite small, it

would also seem significant that the level of English proficiency recorded for persons in the 25-34 age group is not any better than for persons in the 50-69 age cohort. If accurate, and it certainly concurs with much anecdotal evidence regarding declining education levels within the region, then this could be expected to have quite significant implications for the future provision of health services in the East Arnhem region.

A total of 7 interviews were conducted predominantly in English in those instances where respondents showed a clear preference for answering questions in English, and where it was also obvious that the context for interview was clearly understood. Most of these interviews (i.e. 6 or 86%), occurred amongst persons with a very good level of English (Prof 4).

4.2 Hospital-based - Group B

A total of 10 persons were interviewed over a 3-4 week period, when the occupancy rate of the hospital tended to be low. Interviews occurred on an ad-hoc basis depending on who was available and willing to be interviewed. Several interviews were arranged for a later time but did not eventuate, either because of other commitments of the interviewer, or due to an earlier than expected departure from hospital. Interviews were conducted with patients from Gapuwiyak, Numbulwar, Galiwin'ku and Yirrkala / Gunyaŋara communities and came from nine separate clan / nation groups.

4.2.1 Gender and Age

A fairly even gender mix of respondents was obtained, although there is a lack of older females.

Age Cohort	Female	Male	Total
20-29	1	1	2
30-39	4	1	5
40-49	1	1	2
50-59	-	-	-
60-69	-	1	1
Total	**6**	**4**	**10**

4.2.2 Reason for Hospitalisation

The large number of female respondents found in the 'under 40' age group is indicative of their higher frequency of attendance at hospital as escorts or for maternity reasons.

Reason	Number of Patients	Knows Interviewer
Escort	3	1
Maternity	2	1
Operation	2	2
Heart	1	1
Infected Hand	1	1
Boil	1	-
Total	**10**	**6**

A number of interviews (40%) were conducted with persons who did not know the interviewer. This was in contrast to the persons interviewed in community of whom almost all had some pre-existing knowledge of the interviewer and their sponsor organisation (ARDS Inc).

4.2.3 English Proficiency

Age Cohort	Eng Prof 1	Eng Prof 2	Eng Prof 3	Eng Prof 4	Eng Prof 5
20-29		1		1	
30-39			4*	1	
40-49		1	1		
50-59					
60-69	1*				
Total	**1**	**2**	**5**	**2**	**-**

* 2 interviews were conducted with persons who spoke Aboriginal languages other than Yolŋu Matha

Two of the persons interviewed were from Numbulwar and did not speak Yolŋu Matha and so their interviews were conducted in English. Five interviews were conducted predominantly in Yolŋu Matha and a further three interviews conducted in Yolŋu Matha with some English.

5. SURVEY FINDINGS

(from GROUP A - COMMUNITY SURVEY)

5.1 Familiarity with Hospital Environment

Almost half of those interviewed (49%) indicated they only had the one hospitalisation experience in the last 5 years. 13 persons (32%) indicated 3 or more visits to GDH in the last 5 years. The average length of stay was estimated at around 5-6 days, with 8 persons staying in excess of 8 days.

Comment / Variation from Hospital Interviewees - Group B
4 persons (40%) had no prior visits during last 5 years, all were males. Two persons (20%) indicated they had been to hospital lots of times for escort and maternity reasons.

5.2 Food

Eng Prof	Satisfied	Not Satisfied	N / A	Lang Proficiency Total
1	4	3	-	**7**
2	8	2	1	**11**
3	8	1	1	**10**
4	7	4	2	**13**
Total	**27**	**10**	**4**	**41**

People generally expressed satisfaction with the food provided (66%).
Of those expressing some dissatisfaction, those with minimal English and those with good English proficiency were significantly higher. This reflects perhaps the higher level of expectations of those who are more familiar with Balanda culture, as well as the communication difficulties that persons unfamiliar with Balanda culture often experience. In addition there may also be a gender correlation as female outnumbered males 4 : 1 in expressing their dissatisfaction. Also, of the Yirrkala/Gunyaŋara population 57% (all females), expressed dissatisfaction, which may indicate a higher level of expectations arising from their close proximity to Nhulunbuy's shopping facilities and a greater variety of 'Balanda-type' foods.

However it is also significant to note that food did not constitute the primary concern for any person interviewed. It is not high on the list of concerns for most people although it was mentioned by 4 people as an area for improvement. Typical comments were *'food is boring'* and *'more variety needed, especially for breakfast'*. Also one commented that *'Staff should ask patients if they are diabetic'*.

Comment / Variation from Hospital Interviewees - Group B
Generally people were happy with the food, with only one person indicating any concerns.

5.3 Care

The overwhelming majority of persons interviewed (80%), expressed satisfaction at the level of care supplied by hospital staff. Comments such as *'They treated us well', 'looked after me very good', 'we were treated real good'* seemed to refer in the main to 'bedside manner', and the efforts of nursing staff and doctors to try and understand and to learn a little about some aspects of Yolŋu lifestyle.

The following comment probably conveys what many of the people interviewed felt or mentioned briefly about the level of care they received.

> *"Generally staff treat patients and relatives well. Some staff speak strongly to patients. Some patients get upset with this – they think staff are cranky and growling at them rather than trying to teach them something important. I think they are behaving in a disciplined way. It's good to have cross-cultural courses where they can learn about Yolŋu rom and the best ways to talk to people. Staff are good at policing visitors if asked to and will stop people humbugging patients. A couple of nurses I have met are trying to learn Yolŋu Matha – this is good" - **41 yr old female**.*

Several, although happy with the level of care they personally received, expressed some concerns or reservations in regard to the needs of other patients, especially the elderly and also the young mums, who generally have poor levels of English proficiency.

Eng Prof	Satisfied	Not Satisfied	N / A	Lang Proficiency Total
1	6	1	-	**7**
2	9	1	1	**11**
3	7	2	1	**10**
4	11	1	1	**13**
Total	**33**	**5**	**3**	**41**

Those expressing dissatisfaction with the care they received, although small in number (13%), generally had concerns relating to a lack of meaningful information coming from doctors and hospital staff about their sickness and treatment. There was no correlation with age, gender or English proficiency.

Comment / Variation from Hospital Interviewees - Group B

All expressed satisfaction with the quality of care received from hospital staff. Comments such as *"the staff are friendly and helpful"* and *"they look after us very well"* were typical of responses received.

5.4 Explanations about Diagnosis and Treatment

While most persons (80%) expressed satisfaction with the level of care they received, only 11 persons (27%) expressed satisfaction with the level of explanation about diagnosis and treatment provided by doctors concerning their own and/or others medical condition. 46% were clearly not satisfied and a further 27% were uncertain about whether or not they had received a satisfactory explanation.

Explanations about Diagnosis and Treatment

Eng Prof	Satisfactory	Not Satisfactory	Ambivalent	Lang Proficiency Total
1	1	5	1	**7**
2	4	5	2	**11**
3	2	4	4	**10**
4	4	5	4	**13**
Total	**11**	**19**	**11**	**41**

Typical comments made by those expressing satisfaction :

- *I was happy with what the doctors told me, because I kept asking questions until I was satisfied. -* ***41 yr old female Prof 4***
- *I could watch the doctor doing my operation. I believe what he said because I can read his action, that he wants to help Yolŋu.*
  - 63 yr old male Prof 2
- *Yes everything was explained to me as they fixed up my toe.*
  – ***39 yr old female Prof 3***

Those who expressed dissatisfaction did so for a variety of reasons

- *They put a tube down my throat to fix me up, I don't know what they found – Medicine little yellow one, I don't know what it's for. -* ***68 yr old male Prof 1***
- *They gave me six different types of medicine but one small white tablet was the only one that worked. Not sure what its name is. No story from the doctor that I could understand.****65 yr old female Prof 1***
- *I can't remember the name of my sickness or the medicine they gave me – They gave me white tablets, don't know their name. No bottom story -* ***57 yr old female Prof 2***
- *They told me 'You are good, you're doing OK', but I don't think they told me the whole story…. I knew they were testing my heart but*

I'm still not sure what they were looking for or what they thought might be wrong. - ***34 yr old male Prof 2***

- *They took my blood and urine tests but I didn't get any result or any story. It's always like that. They gave me some medicine. I had to take 3 times a day for 7 days and maybe it made me better, I don't know. My sickness must have come from mangimangi*, but it got better quickly so I didn't have to go and find a marrŋgitj* (traditional doctor). -* ***46 yr old male Prof 2*** *(* see Glossary)*
- *Doctors are hiding something. They don't like to tell us the result of the tests we have. Maybe they are frightened to tell us … or they just want to keep the story to themselves. When they send us back they sent the letter to the sister at the clinic but we still didn't hear what the results were from the tests. They just say here is your medicine for your lungs or for your blood pressure and for your sugar – we don't know what the medicine is really for. -* ***44 yr old female Prof 3***
- *My question is about what the doctors say when people die. They never tell us but we know why they died, because of galka*. Why is it that they can't tell the family about the real reason for that person's death ? -* ***53 yr old male Prof 3 (* see Glossary).***
- *When I was in hospital for my bad chest they told me I had pneumonia. I don't know what pneumonia is. When young girls and old people come from homelands they don't feel happy or comfortable because they don't get enough story about their sickness. If they don't get enough story they will straightaway think galka. -* ***35 yr old female Prof 4***
- *Doctors and nurses should give more information when they do blood pressure, take temperature and do tests, but they don't. Doctors wait for people to ask questions but people (Yolŋu) usually don't do that, they expect to be told. Sometimes doctors don't tell the whole truth. They hide some information. They shouldn't do that. -* ***37 yr old female Prof 4***
- *Doctors should tell the full story to the patient about what happened. The patient is the owner of their body……. they (doctors and nurses) should say the name of all the different medicines, how they will work, for what parts of the body and for how long. They should show it with drawing or pictures from a book that I can see and understand. When they talk with other doctors during the ward round I can see they are talking about me but I don't know what they are saying"* ***– 45 yr old male Prof 3***

A considerable number of people seemed unsure about their degree of satisfaction or else gave varying responses according to whether they were talking about a specific event or their general experience.

- *My situation was easy because I understand a bit about diarrhoea and about boils, so I could hear what the doctor was saying. If I had a different kind of sickness then I might find it difficult because I wouldn't understand all the words the doctor was saying. I*

wouldn't know about that sickness and maybe he could not explain it to me properly. - ***38 yr old male Prof 4***

- *At the time I felt I was being told everything by the doctor, but now I realise that there are lots of things they didn't tell us about how the heart could be affected and what could happen without taking the tablets and medicine. -* ***45yr old female Prof 3***
- *I am happy with what they explained to me, and I ask them questions if I don't understand……sometimes I throw them (tablets) in the bin. Same old tablets I take them over and over. They never give me any different medicine. -* ***35 yr old female Prof 4****.*
- *They told me some things. I understood some of what they said. I was too frightened to ask them or find out more things because I am only a young person –* ***27 yr old male Prof 2***
- *Sometimes I understand what staff are saying but not always. Sometimes the English is hard. Doctors hide information that will be upsetting for the patient to hear. They don't want to upset them. -* ***51 yr old female Prof 2***
- *Doctors use that gurraŋay* English (specialised language), which is very difficult for us to understand - same like those government people use when they come to visit. -* ***66 yr old male Prof 3***
- *One good sister, old one, told me full story, but young sister mixed me up a bit……when patient is waiting a long time and they get no story, they feel the doctor is playing with them……Medicine and treatment okay but we want to know what the medicine is and what it will do to our body. Some Yolŋu are frightened for drip or injection because we are not sure what is in it, like we are frightened it might kill us. -* ***46 yr old male Prof 3***

<u>Comment / Variation from Hospital Interviewees - Group B</u>

Explanations about Diagnosis & Treatment

Eng Prof	Satisfactory	Not Satisfactory	Ambivalent	Lang Proficiency Total
1	1*			**1**
2		1	1	**2**
3	3	1	1	**5**
4			2	**2**
Total	**4**	**2**	**4**	**10**

* used daughter as interpreter

As with Group A, this proved to be the area of greatest concern although the smallness of the sample size in Group B does not allow for a rigorous quantitative comparison to be made with the larger community-based survey. More expressed concerns about medication than about the information concerning diagnoses.

5.5 Concerns

Of those expressing concerns, many commented about the lack of sufficient information provided by medical staff. Typical comments suggested *"not enough story", "explanations about tests and medicines", "no story – doctors are hiding information from me" "no one to talk my language to explain" "not enough story – I want a progress report each day"*.

Several people expressed concerns *about 'rules for escorts', 'drunks' and 'learning more about Yolŋu rom*'*, however the main concerns centred around issues of adequacy of communication and lack of information concerning diagnosis and treatment.

In all 35 persons (85%) expressed concerns and many of these had several concerns. These were recorded as 'primary concern' and 'other concerns' and are listed below according to their frequency.

Concern	**Primary**	**Other**
More information about sickness / better communication	19	9
Presence of Interpreter / Educator / Facilitator	5	7
Escorts Rom	3	1
Yolŋu Rom	2	6
Humbug from 'drunks'	1	3
Woken up too much at night	1	-
Very unhappy with care	1	-
Supervision of student doctors	1	-
Valuing of traditional medicines	1	-
Not let old people die in hospital (Y-rom)	1	-
Foreign place	-	6
Homesick / lonely & boring	-	5
Food	-	5
Fear of dying / being killed by Balanda medicines	-	2
Correct names for patients	-	2
Separate rooms for male and female (Y-rom)	-	2
Poor liaison & follow-up	-	1
Follow-up with health clinic on return	-	1
Lack of respect for Yolŋu	-	1
Different treatment of 'scruffy' Yolŋu	-	1
Nil	6	11
Total	**41** (-6)	**63** (-11)

Comment / Variation from Hospital Interviewees - Group B

Concern	Primary	Other
More information about sickness / better communication	3	3
Presence of Interpreter / Educator / Facilitator	2	2
Humbug from 'drunks'	2	-
Homesick / lonely & boring	1	3
Too cold	1	-
Mail at airport	1	-
Yolngu rom	-	2
Separate rooms/facilities m&f (Y-rom)	-	1
Foreign place	-	1
Correct names	-	1
Food	-	1
Nil	-	3
Total	**10 (-0)**	**17 (-3)**

Consistent with those interviewed in Group A, the primary concerns were related to lack of sufficient information about their illness and the need for improved communication. 'Humbug from drunks' also featured as a problem consistent with the earlier study.

5.6 Interpreters

The following responses concerning the presence and need for interpreters arose primarily from the conduct of non-structured conversations rather than from specific questions posed about interpreters. Towards the end of the interview, if it had not already been indicated earlier in the conversation, the interviewer asked whether there was anyone present to assist in understanding what the nurses and doctors were saying, as a means of conducting a check on the context for the information supplied during the course of the interview.

Eng Prof	Interpreter provision	Wanted	Not needed	'Needed' by others
1	1 *	3	-	-
2	1 *	4	1	-
3	0	2	2**	7
4	0	1	6	8
Total	**2**	**10**	**9**	**15**

* interpreter role provided by escort
** both came as patients but also acted as interpreters for others

Use of Interpreters
Interpreters were not provided by THS for **any** patients while hospitalised.

Two patients reported having access to an interpreter, (one a spouse and the other a daughter). A further two patients also indicated that they had acted as interpreters for other patients during their stay in hospital. Two of the escorts indicated that they had acted as interpreters, one also interpreted for several other patients while she was at the hospital.

Several expressed surprise at the lack of utilisation of the Yolŋu liaison person to explain what the doctors were saying to them about their sickness.

Need for Interpreters
As could be expected, the 'expressed need' for the presence of an interpreter was greater amongst those with a lesser standard of English Proficiency and much less amongst those with good English comprehension. This was also confirmed by the higher proportion of persons from 'Proficiency 4' who volunteered that they did not need an interpreter.

However we should also be mindful that in terms of the 'perceived need' for interpreters (i.e. as being 'needed' by others), that this is much higher amongst those of both English Proficiency 3 & 4. Several commented in this regard saying

> *"older people and young mums etc. should have an interpreter …. Should have one doing doctor's rounds to help with asking questions and explaining"*
>
> " *Should have a full-time interpreter to work with the ALO.* "

Only one person for each 'Proficiency 1 & 2' indicated their lack of need for an interpreter. From the above information it could therefore be reasonably inferred that the vast majority of persons with limited English proficiency (i.e. Prof 1 & 2) have a real need for the presence of an interpreter. In at least three cases the need for an interpreter was so obvious and so great, that patients /escorts acted to fill this gap in service provision for other patients. (n.b. This was separate from their original purpose for coming to hospital.)

Comment / Variation from Hospital Interviewees - Group B
As with Group A, no interpreters were provided. One escort acted as an interpreter for her father.

5.7 Comparison to other Hospitals

Of the group surveyed, 10 persons (24%) did not have experience of hospitals other than GDH and a further 5 (12%) did not indicate whether they

had been to Darwin hospital (RDH) or not, and whether or not they had a preference for either hospital.

Comm	GDH	RDH	No preference	N/A	?	Total
Yirrkala / Gunyaŋara	4	-	2	1	-	**7**
Gapuwiyak	-	-	1	1	3	**5**
Galiwin'ku	6	-	4	3	-	**13**
Ramingining	3	3	3	5	2	**16**
Total	**13**	**3**	**10**	**10**	**5**	**41**

Of those who did indicate their preference, four times as many chose GDH over Darwin. Most of the reasons indicated had to do with '*closeness to family and relatives' - for visits and support; GDH staff -'friendlier and more helpful than in Darwin'; Nhulunbuy is - 'smaller, quieter and more friendly than Darwin'; and 'not as far to travel'*. Several indicated a preference for Gove Hospital for non-serious illnesses, but would rather go to Darwin if seriously ill. Also two people indicated that patients are especially fearful of Darwin hospital because if they go into ICU then they are scared they will not come home alive.

Those persons indicating a preference for travel to Darwin all came from Ramingining and stated family reasons as their primary concern. From this it appears that either Darwin or Gove is acceptable to persons living at Ramingining depending on the particular family and whether or not they have close family residing at either place. This is probably also the case for persons living at Milingimbi.

Comment / Variation from Hospital Interviewees - Group B

30% of respondents indicated a preference for Gove over Darwin and did so for reasons of *'closeness to family', 'less noisy' and 'nurses try and understand about Yolŋu culture'*. Another 30%, all being first time admissions from Yirrkala, could also be expected to express a preference for Gove even though they had never been to Darwin.

Those expressing a preference for Darwin did so because of closeness to family / relatives and both came from Numbulwar.

5.8 Commendations

In addition to the satisfaction expressed by most patients (80%) with the standard of care received while present at hospital, a total of 14 persons found cause to offer comments of particular praise or commendation in relation to hospital procedures and/or staff behaviours.

A number of people commented on the positive changes which they perceived in regard to staff attitudes in general. Some expressed their particular appreciation of the efforts taken by some staff towards acquiring a better understanding of Yolŋu cultural requirements, taking care with use of names, being welcoming of visitors and family relatives, and of efforts taken to learn and use Yolŋu Matha language.

In addition several persons, whose previous visit to GDH was more than 15 years ago, were impressed by the improvement in staffing levels and advances in technology, equipment and medical services since their last visit.

Cause for Commendation	**Frequency of Comment**
Some long term staff (= respect & trust)	2
Trying hard to understand more about Yolŋu rom/names etc	2
Better staff attitude than some years ago	2
Staff good to visitors	2
Better level of care - more staff	2
Operations performed properly / professional	2
Efforts to learn Yolŋu language	2
Special equipment now available	1
Doors locked at night (drunks)	1
Respectful of Yolŋu rom – don't move body till singing finished	1
Total persons (making above comments)	14

Comment / Variation from Hospital Interviewees - Group B

Although 100% of patients expressed their satisfaction with the level of care they had received, there were no particular expressions of high praise evident. Perhaps this is reflective of all patient's overwhelming desire to return home as soon as they are well enough, and the lack of opportunity for them to reflect on the totality of their hospitalisation experience.

5.9 Improvements

A total of 29 persons had one or several suggestions concerning a range of improvements to assist Yolŋu patients and/or escorts during their hospital stay. The identified area of greatest need concerned the provision of additional information and better explanations regarding diagnosis and/or treatment, and in particular more information concerning 'medication'.

Improvement	Frequency
More explanation from medical staff	9
Interpreter / Educator (YM)	7
More cross-cultural training	6
Learn more Yolŋu language / names	3
Music / christian music	3
Food	3
More Yolŋu employed @ hospital	2
Regular 'x-ray check-ups' for seniors	1
Chaplain (speaks Yolŋu Matha)	1
Accommodation	1
Bus	1
Credit agency	1
Separate ward for young people	1

A closely associated need identified by respondents was the provision of meaningful medical information to patients by means of Yolŋu Matha, either through an interpreter working in association with medical staff, by means of an educator or by the use of an interpreter team (Balanda & Yolŋu working together).

The next most frequently identified area for improvement concerned the provision of cross-cultural training for hospital staff, either to build on the basic understandings they have already acquired, or to begin the process of becoming more informed about Yolŋu culture, protocols, language and law.

Of those persons with minimal English ability, most (72%) had few ideas about how the hospital environment could be improved as the table below shows, even though the vast majority (86%) reported dissatisfaction with the explanations provided to them concerning both diagnosis and treatment. This indicates the degree to which those particular Yolŋu patients, who experience a lack of meaningful communication, are so easily overwhelmed by their hospitalisation experience. It is therefore important to note that a much greater proportion of those with good English proficiency were able to identify and articulate the need for hospital staff and doctors to have more cross-cultural training as their highest priority for improvement of the hospital environment in order to make it more accommodating of the needs of Yolŋu.

Eng Prof	none	More story from medical staff	Interpreter / Educator	Cross-cult training
1	5	1	1	-
2	3	3	2	2
3	2	3	2	-
4	2	2	2	4
Total	**12**	**9**	**7**	**6**

Comment / Variation from Hospital Interviewees - Group B

Very few suggestions were made concerning improvements that could be made, *'not sure'* and *'hard to say'* being common responses. Suggestions made were *'christian fellowship on a regular weekly basis'; 'traditional foods'; 'hunting trips' ; 'too cold in the ward – make it warmer'*.

Most gave the impression of 'wanting to go home' as being the major need or improvement that they would like to see realised.

A further two areas of patient responses and comments were sought in order to try and form an overall picture of ex-patient perceptions concerning GDH, and the extent to which their recent hospitalisation experience(s) had impacted on, or changed, this perception. Patients were asked to talk about the circumstances surrounding the decisions for their entry into hospital and their feelings about being hospitalised. In addition, their views concerning whether or not they thought hospitalisation had been beneficial for their particular health problem, was also documented.

5.10 Patient Perception of Hospital

More than half of those interviewed indicated that they were happy to go to hospital, some presenting themselves, while others generally accepted the advice of the referring sister or doctor that hospitalisation was necessary for the purposes of treatment and/or diagnosis. Those expressing fear or reservations of some kind concerning the desirability of sending sick persons to hospital, either in relation to their own particular circumstances or for Yolŋu patients in general, were also recorded.

A significant number of patients talked about their fears that something bad could happen if they or other patients were sent from their home community to Gove.

> *I went with my wife to the hospital to be with her. I was worried to let her go by herself, because Gove is a different place. We don't really know the (Yolŋu) people there and what they will do or what might happen. Something bad could happen in that foreign place. If we go for a day trip that's alright, but we don't want to stay overnight.*
> – ***53 yr old male Prof 3.***

Some of these fears related to directly to a fear and mistrust of Balanda doctors and/or medical procedures that could cause people to die. Other fears related to their feelings of uncertainty about what might happen in a strange and foreign environment about which they had little comprehension and over which they had no control.

> *When I was in hospital in Darwin I was very sick. They changed the nurses during the night. I saw them, that they didn't write down or sign their names. That made me worried that they might do something*

*to me. I didn't sleep that night … I was too scared**. - 44 yr old female Prof 3.***

Still others, like the 53yr old above, had fears about travelling into unfamiliar territory owned by other Yolŋu clans and to which they had not been invited; and where, as a direct consequence, something bad might happen to them causing their health to further deteriorate.

Eng Prof	Confidence in GDH /Hospitals	Some reservations or fear	Total patients
1	2	5	**7**
2	6	5	**11**
3	5	5	**10**
4	11	2	**13**
Total	**24**	**17**	**41**

The preceding table indicates a number of findings.
Firstly it is those persons with very good levels of English comprehension who are most likely (85%) to express any real confidence or faith in hospitals and the ability of Balanda medicines and medical procedures to bring about health and healing. Those persons with 'satisfactory' and 'conversational' levels of English proficiency are equally divided between those believing that hospital is 'a good place to go when you are sick', versus those whose fear of foreign places and situations suggests a belief in the importance or significance of other factors to make people better.

Most persons with minimal comprehension of English expressed some reservations or fears about being hospitalised. As well as a lack of comprehension of what is being said and explained to them about their sickness, the hospital environment is foreign, with many new and unfamiliar practices. People's fears about what might happen to them are consequently heightened.

5.11 Satisfaction with Hospitalisation Experience

While 78% of patients reported a satisfactory outcome concerning their hospitalisation experience, those with minimal levels of English proficiency had much less satisfactory outcomes. Lack of understanding, and a complete breakdown in communication in the absence of any interpreting provision, were the main causes for concern, which contributed to the poor level of health care received.

Nothing was explained to me. I just went there (to hospital) and they did something (medical procedure) and I came back again. ***– 65 yr old female***

Another patient reported a high level of satisfaction with everything at the hospital, but then went on to say

> *"……after sending me to Darwin, they still couldn't give me any idea what was wrong with me, so I went to our own traditional doctor (marrŋgitj). He found out my problem was with my liver and too much sugar. Since then I have had no more trouble with feeling giddy".* ***– 62 year old male***

(n.b. In all, three of the nine persons who were not satisfied with their hospitalisation experience reported seeking assistance from a traditional doctor upon returning home.)

The high level of ambivalence felt towards hospital by many older people and/or those with poor English comprehension skills is perhaps summed up in the following comments by a patient who, although expressing satisfaction with the outcome, still had a number of reservations about her hospitalisation experience.

> *"Yes it was good that I went to hospital for an operation on my boil……..but (hospital) is a strange and foreign place. I can only go there if I am really, really sick."* ***- 62 year old female***

Eng Prof	Outcome Satisfactory	Not Satisfactory	Total Patients
1	3	4	**7**
2	10	1	**11**
3	9	1	**10**
4	10	3	**13**
Total	**33**	**9**	**41**

Perhaps the most significant finding was that eight of the nine persons (89%) reporting a lack of satisfaction also expressed their concerns about the lack of sufficient information concerning diagnosis of their particular sickness, or for the person they had escorted to hospital.

The remaining person of the nine who were dissatisfied did not report any communication problems, and was atypical of the younger articulate persons who participated in the survey, being the recipient of an unpleasant hospital experience. This 36 year old female, with good English language skills and many years experience as a health worker, had high expectations of a favourable outcome from a routine day-trip to hospital for an x-ray, along with several other patients from her home community. However, after spending 4 nights at the hostel, undergoing dietary preparation each morning for an x-ray that did not eventuate until the second last day, and listening to so many changes in plan and 'excuses' about why the examination could not proceed; she became was so utterly distraught and angry that she is not sure if she ever wants to go back to hospital again!

5.12 Patient Satisfaction Rating

Finally, the researchers analysed the data provided and constructed the following rating system to record patient satisfaction. This was done in order to complement the above findings and obtain some sort of objective measure of ex-patient's attitudes towards hospitalisation, the degree of satisfaction experienced and the extent to which different factors are instrumental in determining patient satisfaction.

Rating of Patient Satisfaction
A - No Complaints
B - Good, but some concerns
C - Quite a few concerns
D - Unhappy about most things

Eng Prof	A	B	C	D	Total Patients
1	2*	-	4	1	**7**
2	2	4	5	-	**11**
3	2	5	2	1	**10**
4	2	7	3	1	**13**
Total Patients	**8**	**16**	**14**	**3**	**41**

* One of these patients was happy with everything, but recorded a less than satisfactory medical outcome (see below)

According to the above ratings there is a very strong correlation between the language proficiency of patients and their degree of satisfaction. 70% of those from Proficiency 3 & 4 expressed a high level of satisfaction with few concerns, compared to 29% for those with minimal English. (n.b. One elderly patient interviewed was very 'experienced' within the hospital environment and reported having travelled to hospital "lots of times". However it was very obvious to the interviewer concerned that the chronic language difficulties encountered at the hospital provided a severe impediment to the treatment of his particular medical condition.).

Using this same scale, there also appears to be some correlation in relation to 'satisfaction' and 'location', with patients from Ramingining (9 out of 16 = 56%) expressing a greater number of concerns than those from Galiwin'ku (4 out of 13 = 31%). Both communities had similar profiles in terms of language proficiency (prof 3 & 4 =56% & 54% respectively) but a greater number of older persons were interviewed at Ramingining (44% compared to 23%). Despite the low numbers of persons interviewed from Yirrkala / Gunyaŋara, it can also be reasonably inferred from earlier comments concerning hospital comparisons, that persons resident at Yirrkala / Gunyaŋara have a strong preference for admission to Gove Hospital due to its close proximity. Combined with the lower age profile (57% < 45yrs), location could well be a significant factor as to why most persons (86%) interviewed from Yirrkala /

Gunyaŋara recorded few concerns about their recent hospitalisation experiences.

6. INTERPRETING THE FINDINGS

The following section seeks to identify some of the more common themes arising from the interviews, present further interpretation and provide additional information gained by observations made during the conduct of the interviews. Understandings held by the interviewers from their history of working in the East Arnhem region generally, and their pre-existing knowledge of and relationship with specific persons interviewed separate from their hospitalisation experience, are also drawn upon where necessary to inform this interpretation.

6.1 Communication Difficulties - Bäyŋu dhu<u>d</u>i-dhäwu

As discussed in the preceding section, it is very clear that the most common complaint and primary concern expressed by ex-patients has to do with the lack of sufficient information and/or explanation concerning diagnosis and treatment. Of those interviewed, most (i.e. 30 persons or 73%) expressed either a lack of satisfaction or some ambivalence with regard to the explanations offered.

Patients are looking for the *dhu<u>d</u>i-dhäwu* (bottom story) behind their sickness – an explanation that would tell them not only the name of their sickness, but also where it came from. The explanation needs to be a <u>sense-making story</u> which clearly shows the patient exactly what it is that is making them sick. For example in the case of a pathogen - what it looks like, size, shape, general characteristics, how it behaves in the human body and how it can be removed or destroyed.

In order to be meaningful to the patient, the explanation needs to take into account what the person already knows about their own body, about sickness and disease in general, and utilise those understandings to explain what is happening inside the patient's body with this particular illness. It needs to demonstrate to the patient's satisfaction how the planned treatment will bring about health and healing. To be meaningful it needs to use vocabulary which the patient is both conversant and comfortable with.

As can be seen from some of the comments reported in the previous section, many patients were sceptical about whether they had been told the full story about their sickness. Analysis of these comments by the researchers reveals a number of sub-themes which are explored below.

a) *"Doctors are hiding something"*

A common perception held by patients was the belief that Balanda doctors purposely kept information secret from the patient for reasons known only to the doctors themselves. It is also clear that patients disapproved of this 'behaviour' - *"they shouldn't do that"*- , believing that it is the patient's right to have full disclosure of their sickness and proposed treatment, because the patient is the "*rumbal-wa<u>t</u>aŋu* (body owner) ". These perceptions were

observed to be commonly held, irrespective of English proficiency, age, gender or number of visits to hospital. Similar findings were documented by Reid 25 years ago, and are known to be still commonly held by many Yolŋu.

b) "*If they don't get enough story they will straightaway think 'galka'*."

One of the consequences of poor communication is the information vacuum that results following the breakdown in communication between doctors or nurses and patients, as all the foreign or unfamiliar words and concepts that are typically used to explain fail to create a meaningful picture for the patient. People hear foreign Balanda words and medical terms through their own cultural constructs or ontological frame of reference (also sometimes referred to as 'world view'), such that the words often take on a single or literal meaning, with the effect that the contextual meaning is obscured or totally misread. Examples of such words are "heart attack", "stroke", "medicine" and many others. In the case of a 'heart attack' for instance which for Yolŋu is an alien disease resulting from recent changes in lifestyle, most Yolŋu would be led to believe that some person, agent or foreign body was trying to attack their heart. A 'stroke' on the other hand is something totally new in terms of both vocabulary and experience and so may mean something to do with soothing a sick person or animal, (stroke of a pen!) …. but what is it really ??

In the absence of any meaningful story, the patient is left to ponder any number of possibilities as to why they are sick (e.g. which law/s they may have broken and are being punished for; which clan group, family or person they may have transgressed or deeply offended; or else perceive themselves as a victim of a malevolent supernatural attack from an unknown assailant).

The sense-making stories for people are those with which they are familiar, which come out of their world view and experience; and so stories about galka* are an increasingly common part of people's causal explanations about ill-health in a very contemporary and rapidly changing world. Many of the familiar ways from the past are rapidly changing or disappearing and many foreign / new things are taking their place, as well as the occurrence of new sicknesses that people have never seen or heard of before. People are fearful of entering into unfamiliar social territory where there are many strangers and few close family or kin to care for them.

In addition, there is the suspicion that Balanda doctors themselves may indeed be galka because, as Reid notes, many of their practices "bear a striking resemblance to certain forms of sorcery". This view is supported by the following account.

Some doctors kill people with medicine. They ask if they can give you medicine to help you sleep / relax, but really it will kill you ……..(other people think this as well). Old or young people can be killed. Not all doctors kill people - some do. - ***51 yr old female Prof 2.***

* See Glossary

Amongst almost all patients there is a very strong desire for doctors to improve their communication skills and explain in some meaningful detail about what has been happening, is currently happening and/or is soon to happen, in terms of the progression of a disease, before it actually occurs. If this were to consistently occur, it is likely that Yolŋu would possess other evidences or explanations to help then to make sense of what happened or caused a particular person to die. As a result, sorcery will be more likely discounted as the causal explanation in that particular case. However this is not what is happening at the moment in the vast majority of cases, as the following account shows.

Doctors don't tell us why people die but we know why they die. They die from galka . They never tell us the truth about what happened, why that person died. The doctors know it is galka who killed that person but they won't say or tell us. They are healthy one day and then the next day they just die. And we don't get any story from the doctors. - ***41 yr old female Prof 4***

c) "*I went to see the marrŋgitj**"

It would not be unusual for a person with a persistent and serious illness, who believes that their sickness has a supernatural origin, to want to see a specialist who they think is able to accurately diagnose and also treat their particular sickness or condition.

In the absence of any meaningful information, the following account shows how people are likely to make sense of their hospital experience.

They took my blood and urine tests but I didn't get any result or any story. It's always like that…….. My sickness must have come from mangimangi, but it got better quickly, so I didn't have to go and find a marrŋgitj (traditional doctor). -* ***46 yr old male Prof 2.***

According to the Yolŋu world view, a marrŋgitj is a "specialist who has exceptional knowledge and powers ……..(and) is only called upon to treat serious or chronic illness that does not respond to the usual medications, which any person can administer" (Reid 1982 p 167). Traditionally the work of the marrŋgitj was complemented by herbalists who prepared and administered a range of naturally occurring medicines, performing a similar function to that now conducted by the clinic sister and health workers.

d) "*I believe God that he healed me"*

While Balanda doctors and Yolŋu marrŋgitj are both perceived to have special knowledge and skills that 'ordinary people' do not possess, the bottom line for many of the people interviewed, in terms of 'life and death' matters and also for 'healing', is God. Each person has their own understanding and also their own experience of who and what they believe God to be and to possess. Some of these responses are detailed below.

* See Glossary

The marrŋgitj from Bulman came and fix me up here after I came back from Darwin hospital. I was still sick and he looked at me and he took that thing out from my side. I was healed. I believe God that he healed me, he used that clever person (marrŋgitj) to help me get better. ***– 68 yr old male Prof 1****.*

They don't give us the full story about where our children's sickness came from. (pause)… It's true isn't it, that if we believe in God then we won't get sick and have to come to hospital. We get sick because we sin. That's right eh ? ***- 22 yr old female Prof 4*** *.(Interview conducted at hospital – Group B)*

I trust Bäpa (God) first, and doctors second to look after me. That means I will go to hospital. ***- 44 yr old male Prof 3.***

Prayer is the main one. Hospital is not the main thing (to put one's trust or faith in for healing). Yolŋu should not be frightened, because God is there in the hospital too….. We go to different hospitals (Gove, Darwin or Adelaide) according to how serious the problem is. ***- 57 yr old male Prof 2****.*

If I don't know something I just ask them. I believe in God and God looks after me – ***62 yr old male Prof 2.***

It's not the doctors or medicine that made me well. It's Garray (Jesus) who made me better through the blood that flows through my veins. He makes it new. ……Half the hospital staff are christian people, I know. They believe in God, that God heals people. Others I don't know; maybe they are working good or maybe not. ***– 57 yr old female Prof 2.***

Belief in, or reference to, God was made by those who had both positive and negative attitudes in regard to their hospitalisation experience. While some of the above persons made reference to God to allay their fears, others expressed a desire and confidence to go to hospital <u>because</u> God was there, (and in one case the respondent was also able to help other patients with their communication needs). Implicit in most people's comments was the need for health professionals (and especially doctors) to be (God's) agents of healing. In order to do this, and to win the patient's trust and confidence, good communication skills are also necessary.

e) "*They should say the names of all the different medicines, how they will work ….*"

The communication breakdown and consequent lack of trust which subsequently occurs around the lack of provision of satisfactory explanations is not only a common experience, it is also profound. It has frequently been the experience of the researchers, during the conduct of this survey and also during many previous medical interventions, that Yolŋu want and require <u>*much more, not less, explanation / information*</u>, than do Balanda patients.

……. they (doctors and nurses) should say the name of all the different medicines, how they will work, for what parts of the body and for how long. They should show it with drawing or pictures from a book that I can see and understand. ***– 45 yr old male Prof 3***

Doctors and nurses should give more information when they do blood pressure, take temperature and do tests, but they don't. Doctors wait for people to ask questions but people (Yolŋu) usually don't do that, they expect to be told. - ***37 yr old female Prof 4***

Medicine and treatment okay, but we want to know what the medicine is and what it will do to our body. Some Yolŋu are frightened for drip or injection because we are not sure what is in it, like we are frightened it might kill us. - ***46 yr old male Prof 3***

In particular, explanations about medication were especially troublesome for patients and there are a number of reasons for this :

i) when dealing with either linguistic and/or cultural difference it is always much easier to communicate when dealing with 'tangible' rather than 'intangible' topics or objects. The medical condition with which some patients presented (e.g. maternity, infected thumb, skin pierced by stingray barb etc.) are very familiar and are also easy to see, so diagnosis is often not an issue. On the other hand, medicines, although seemingly very tangible, often look the same (e.g. "all the tablets were white"), and once inside the body it is totally incomprehensible to <u>all</u> patients what they actually do, because it has never been satisfactorily explained to them.

ii) Balanda doctors, Balanda medicines, Balanda hospitals – all are foreign and alien for the vast majority of patients. Unlike the vast majority of Balanda patients, Yolŋu do not straightaway have faith in Balanda doctors or in Balanda medicines, precisely because the whole Balanda medical system is *foreign*. While it is true that Yolŋu perceive most things Balanda to be very powerful, there is also a strong ambivalence expressed towards things that originate from 'outside', which are not well understood, and do not always deliver according to people's expectations. Ambivalence towards Balanda medicines therefore is very pervasive. Traditionally, Yolŋu had faith in their own herbalists, doctors and medical treatments because it was not foreign, it was 'theirs'. However this is now often not the case, because they are perceived as being inferior to, and not as powerful as, Balanda medicines.

iii) Balanda medicines are viewed with great suspicion because they are not only powerful for healing purposes, they can also kill. Some medicines, especially those administered as injections, are seen to have almost supernatural qualities (e.g. anaesthetics can put you almost instantly to sleep, and early on in Arnhem Land people's experience, injections "magically" cured yaws and other infections). Conversely, many other medications such as 'tablets' are perceived as

"useless" and are either discarded or prematurely discontinued if the patient perceives no change in their condition *……sometimes I throw them in the bin. Same old tablets I take them over and over. They never give me any different medicine.* - ***35 yr old female Prof 4***. They wonder why the nurses or doctors are punishing or tormenting them by not giving them the right (powerful) medicines that they '*know'* are within the power and ability of the Balanda to give.

In the absence of meaningful explanations about things foreign, unknown and unseen, and without a meaningful exchange of information between doctor and patient about how it will work, 'a *magic* something' would seem quite a reasonable conclusion to come to. In those situations where communication breakdown has occurred, frequency of visits to hospital or frequency of administering the same medication does not equate to better outcomes, only to more confusion.

f) "*I didn't ask the doctor any questions…..*"

Traditionally, Yolŋu are socialised to respect their elders and those in authority. They are also taught to value, and even pay for, knowledge. It is therefore considered 'rude' or 'impolite' to ask questions, especially of elders or when in someone else's territory. The strange and alien nature of hospitals and the Balanda medical system therefore presents a number of challenges and barriers to Yolŋu. As patients, they are expected to follow Balanda protocols and behavioural norms which they often do not feel comfortable doing, or else completely disagree with. Also, they may not understand the function or wider context of the particular cultural practice.

I didn't ask the doctor any questions because he was the doctor and I was the sick person. I was waiting for him to tell me a detailed report of my condition ….. but he didn't say. ***- 45 yr old male Prof 3***

Young people in particular, find it extremely difficult to ask hospital staff about their sickness and this was observed and commented on during the survey.

I was too frightened to ask them or find out more (information) because I am only a young person. ***– 27 yr old male Prof 1***

Doctors wait for people to ask questions but people (Yolŋu) usually don't do that, they expect to be told. - ***37 yr old female Prof 4***

Yolŋu are always the ones who are expected to change and to conform, and of course many do, with significant numbers of persons with reasonable English (proficiency 3 and 4) reporting that they ask questions when they don't understand. Observations of the researchers suggest however that this is easier said than done. Most Yolŋu, despite their English-speaking skills, are still intimidated by Balanda in general and especially by 'high people' like doctors, just as most Balanda patients are. Even though many Yolŋu do ask questions, the number of questions asked by any one person are usually few, and often many questions remain unasked and therefore unanswered.

However the onus for change, especially in the interests of improved communication, should really rest with those who are empowered to do so. Rather than simply acting in habitual and culturally comfortable ways, medical staff, and doctors in particular, need to apply some thought, effort and creativity to finding better ways to communicate with people of another culture whose first language is not English. The use of pictures, drawings or diagrams were some of the practical suggestions offered by those interviewed.

g) "*Sometimes the English is hard*."

Another difficulty experienced by many patients, that is even more problematic than the above, is the barrier to communication caused by differences in language. None of the Yolŋu persons interviewed were assessed as having a proficiency with speaking and comprehending English to the level of an adult native English speaker. Consequently, much of the everyday language used to explain or communicate about health, and which is taken for granted by most Balanda, is not fully understood even by Yolŋu with good English conversational skills. This is because spoken language contains many concepts which are culturally-embedded and into which the native English speaker has been socialised from birth. Consequently, when used in a health context, they become problematic.

> *What is Panadol ? Is it good to always have Panadol from the clinic for every sickness that we have ? What effect is it having inside our bodies ? Is it good or is it doing damage ?* ***– 62 yr old male Prof 3***
>
> *They told me I had pneumonia. What is pneumonia ? I don't know what it is. Another time they gave me pethidine. Its strong medicine – it makes you feel sleepy. -* ***35 yr old female Prof 4***
>
> *Doctors and nurses should give more information when they do blood pressure, take temperature and do tests, but they don't. –* ***37 yr old female Prof 4***

'Blood pressure', 'asthma', 'heart attack', 'pulse', 'antibiotics' etc. are all familiar words to Yolŋu patients with reasonable English-speaking skills and also to those who are frequent visitors to the local clinic. However when asked to explain what they are, look like, or do, the average patient, and also most health workers, readily admit that they do not know.

When it comes to understanding other more specialised medical terms, Yolŋu feel especially marginalised and also victimised.

> *When they talk with other doctors and nurses during the ward round, I can see they are talking about me but I don't know what they are saying.* ***– 45 yr old male Prof 3***

Doctors use that gurraŋay English (specialised language terms), which is very difficult for us to understand - same like those government people use when they come to visit. -* ***66 yr old male Prof 3***

If I had a different kind of sickness then I might find it difficult, because I wouldn't understand all the words the doctor was saying. I wouldn't know about that sickness and maybe he could not explain it to me properly. - ***38 yr old male Prof 4***

Some Yolŋu recognise that the terms used by staff are simply a further dimension of the communication gap that exists between Yolŋu and Balanda, because they have openly discussed and analysed it with Balanda speakers of Yolŋu Matha in other contexts. Many others however perceive that Balanda possess a special secret language which is known only to Balanda, and which they purposely use in order to hide information from Yolŋu.

It is obvious that all persons of English Proficiency 1 find most of the English used very difficult to understand. Further, it is the opinion of the researchers that all those interviewed of Proficiency 2 would also find much of the English too hard, despite the fact that 4 persons (36%) said that they found the explanations given satisfactory.

A closer look at those particular persons and their responses indicates the reason for their satisfaction with understanding their particular sickness and treatment. Two of the patients had surgical procedures performed where they were both able to watch the operation being performed, (one to remove a stingray spine and the other to have minor surgery on an ankle) and both were extremely happy with the outcome. One of these also had his wife present to help with his interpreting needs. A third patient last visited GDH 4 years ago for a check-up for diabetes at which time the doctor reported that everything was fine and the patient was able to return home that same day. The fourth was an escort who had gone for the circumcision of her son, an elective and fairly routine procedure with which she expressed complete satisfaction and confidence in the doctor's performance.

However it is also interesting to note that only one person (i.e. 1 out of 18 persons of Prof 1 or 2) openly expressed their lack of need for an interpreter to be present. This was the fourth person (escort for her son's circumcision) as discussed above.

6.2 Escorts

Escorts was the third major area of concern identified by patients. Escorts are commonly used by Yolŋu patients and/or families in a variety of roles in order

* see Glossary

to meet the joint requirements of patient and family needs back home, namely:

- *as companion* in order to help patients. To talk with patients in their own language about familiar topics and stop them from feeling lonely or homesick and to prevent the patient from absconding from hospital or leaving prematurely before treatment is finished.
- *as a witness* to allay the fears of family back home in case anything bad should happen to the patient from either Balanda medical staff or from strange Yolŋu in 'foreign' territory.
- *as helper* to perform a wide range of assistance to the patient e.g. massage, help with eating meals, toilet/shower routines (if of the right sex, age and relationship), plus shopping and banking needs.
- *as communicator* to the family back home, relaying messages and reporting on patients progress and condition.
- *as facilitator of hospital visits* for the patient by nearby relatives or by other friends/associates of the patient.
- *as interpreter / facilitator of communication* between staff and patient as requested by patient, staff or as the escort perceives the need, to act in this way in the absence of other communication services.

A number of people had strong views related to escorts. One woman, in particular, expressed great concern for young antenates who, in her view, have an intense need for an escort to help them cope with the birth of their first child, especially if they have had no previous experience away from home in hospital. She also described the distress that mothers feel watching their young daughters going off to hospital for the delivery of their babies alone. Another woman from the same community also articulated these concerns about young antenates, that are also well documented in Kildea's (1999) recent report. The second area of concern was for old people. Several interviewees were quite adamant that old people need to have a family member with them.

The appropriateness of, or priority given to, some or all of these roles of the escort, when viewed from the perspective of the Balanda health system, is not necessarily the same as that of Yolŋu. For instance nursing and medical staff may see the main role of the escort to be 'interpreter', thus abrogating THS of the responsibility to provide an interpreter service to meet the communication needs of patients.

A Balanda perspective may also see that wider budgetary concerns and the availability of the necessary resources to provide the required level of support to patients needs, in some instances, to override their statutory responsibilities regarding the rights of the patient. For instance, the issue of 'informed consent' and the right of patients to have the necessary information mediated to them in their first language, were clearly not evidenced from the research findings.

6.3 Yolŋu Rom

Another major area of concern expressed by patients relates to the general lack of knowledge and understanding of hospital staff about Yolŋu culture or Yolŋu rom*. This incorporates a wide variety of subjects such as appropriate behaviour regarding interpersonal contact and communication; an understanding of 'gurruṯu' (system of family and extended family relationships) as the basis for social organisation and the enacting of law in Yolŋu society; 'mälk' (classification system of general roles according to relationship); terms of address and use of appropriate names for patients according to gender, age, family relationship and familiarity.

Several Yolŋu respondents expressed their appreciation of the efforts made by some hospital staff to acquire some initial understandings of Yolŋu culture and language. In addition, a number of Yolŋu commented favourably about changes in staff attitudes over the last 5 to 8 years observing that staff were *"friendly"*, *"wanted to help"*, *"interested to hear what I was thinking"* and *"interested to learn from Yolŋu"*. Several, who were infrequent visitors to hospital, commented how they thought that staff were different now and had *"improved a fair bit since then (70's)"*, and *"staff attitudes were much better than before ('84)"*.

However some also expressed concerns or reservations about the behaviour of a minority of staff who they perceived to be either discriminatory, or not particularly interested in learning from Yolŋu.

> *- Staff are okay with relatives and visitors when they looked clean and respectable. They treat Yolŋu who looked scruffy in a different way - not as well.* ***- 33 yr old female, Prof 4****.*
> *- All of them are dhuŋa (ignorant/unlearned) for Yolŋu rom. They should learn. I can teach them – but I don't know if they want to learn……. They need to have more practice listening to Yolŋu so they can learn and understand how to listen. If they can't listen for me and for Yolŋu, any Yolŋu, then they are not the right people to work there….. Balanda and Yolŋu need to listen to each other's feelings and each other's law. -* ***63 yr old male Prof 2****.*

Others expressed what many Yolŋu are known to feel, a desire for more 'two-way' learning to occur in the hospital environment.

> *- All Balanda working with Yolŋu should learn Yolŋu Matha and Yolŋu should learn English* ***– 41 yr old female Prof 4***
> *- They have to learn from us like we have to learn from them, so Balanda and Yolŋu can live together in good relationship.* ***– 66 yr old male Prof 3***

* see Glossary

6.4 Fear

We have already discussed briefly the fear that many Yolŋu feel about going to hospital for treatment. Fear of 'galka', fear of 'Balanda medicine', fear of strangers and strange environments, and fear of dying at the hands of Balanda doctors and medical staff, are all real fears for Yolŋu.

> *- Some doctors kill people with medicine. They ask if they can give you medicine to help you sleep / relax, but really it will kill you. -* ***51 yr old female Prof 2.***
>
> *- Some Yolŋu are frightened for drip or injection because we are not sure what is in it, like we are frightened it might kill us. -* ***46 yr old male Prof 3***

It is the aspect of 'not knowing' the rationale or reason behind many of the Balanda cultural practices, that is disconcerting for many Yolŋu. For instance, what are the different sorts of medicines that a doctor could use? what is in the medicines? where do they come from? what powers do they have? why do doctors sometimes use 'strong' medicines and sometimes use 'weak' ones ? These are all mysteries that are disempowering for Yolŋu, especially when they don't know what the doctors are thinking and what might foreseeably happen to them.

As explained by one patient

> *People run away from hospital a lot of the time because they are scared of the hospital…staff…operation… or that they're going to be given some bad or harmful treatment of some kind****. - 33 yr old female, Prof 4.***

Some would argue that these fears are best addressed or nullified by providing good quality medical care in order to facilitate positive medical outcomes. While it can easily be demonstrated that positive outcomes are achievable for patients who are both confident and fearful regarding hospitals (see table below), it can also be seen that fearful persons report a lower level of satisfaction with their hospitalisation experience (65%) than do those who are confident or familiar with the Balanda hospital environment (88%).

	Outcome Satisfactory	**Not Satisfactory**	**Total**
Some fears / reservations	11	6	**17**
Confidence in Hospitals	21	3	**24**
Total	**32**	**9**	**41**

However the above does not necessarily indicate any significant overall attitudinal change by the patient in relation to Balanda hospitals, as hospitals still remain essentially 'foreign' environments where many things happen without their knowledge and without their informed consent. Of those 11 persons who had a satisfactory outcome but also did not generally feel

confident in hospitals, their level of overall satisfaction with their hospital experience showed that most (64%), had reported 'quite a few concerns' = Rating C.

While attention to better communication is therefore more likely to allay patient's fears and produce more favourable attitudes to hospitals, there is also the obvious need for Gove District Hospital to continue to provide good quality professional care (i.e. provision of good patient care, accurate diagnosis and correctly performed medical procedures) that was widely reported, so that people's fears are not added to further.

7. ISSUES ARISING – RECOMMENDATIONS

7.1 Interpreters / Communication Facilitators / Hospital-based Educators

Attention to the language needs of Aboriginal persons coming as patients to Gove District Hospital is an essential and critical area of need in order for Territory Health Services to fulfil its 'duty of care' responsibilities to Aboriginal patients.

> *Language is what makes it very hard for many Yolŋu to get the same standard of medical treatment like Balanda get, because medical staff and patients can't understand each other.* ***– 66 yr old male Prof 3***

The survey reveals a glaring lack of language services provision at GDH. The current strategy of employment of a hospital-based Aboriginal Health Worker and an Aboriginal Liaison Officer to work at the hospital has not and cannot adequately meet this need. The de-facto use of some escorts as 'interpreter substitutes', while better than nil provision, does not adequately meet all the communication requirements of that particular patient and could on occasions be the unwitting source of incorrect information. Also, there are many patients for whom an escort is not provided.

Also, in light of the fact that a significant proportion of the younger generation of Yolŋu (i.e. those in the 25-34 age group) possess a lesser standard of English Proficiency than those in the 35-50 age cohort (see section 4.1.3), language services will continue to be in demand for many years to come.

There is a critical need for language services to be available to *all* Aboriginal patients (Yolŋu and non-Yolŋu) who possess 'minimal' or 'conversational' English language skills, (categorised in this survey as English Proficiency '1' and '2').

The type and nature of these language services needs to be 'crafted' and 'developed' to provide a wide range of functions to cater for patient's communication needs. Further, a 'team approach' (i.e. provision of a language-team) is required if language services are to be both 'adequate' and 'sustainable'.

As Yolŋu patients constitute the vast majority of patient admissions to GDH and only 'Yolŋu Matha-speaking' ex-patients were surveyed, the comments and recommendations which follow are specifically referenced to the needs of Yolŋu.

Facilitation of the communication needs of 'Yolŋu Matha-speaking' patients is the number one priority. Sometimes those needs are for the provision of an

interpreter so that doctor or nursing staff and the patient can accurately hear and understand each other. At other times an 'education' function is required.

Additional to these functions is the need for patients to feel 'accepted' and 'more at home' within the alien hospital environment. *When Yolŋu hear their own language being spoken by strangers it gives them confidence, makes them feel braver in a strange place* ***– 33 yr old female Prof 4***

In the absence of any professionally qualified interpreters to NAATI Level 3 (Yolŋu or Balanda) within the East Arnhem region, how are these needs to be met ? ……The following suggestions / recommendations are offered :

Recommendation 1

The provision of a Language Services Team at GDH to facilitate the communication and education needs of Yolŋu patients. (In addition to the employment of several Yolŋu persons to function in the roles of hospital liaison and trainee interpreter / educator, this team would also need to incorporate the services of an English-first-language health educator. The educator would need to possess Yolŋu-Matha skills sufficient to enable them to work in a dynamic team relationship with several Yolŋu co-workers.)

The rationale for the above recommendation is grounded in many of the comments and concerns expressed during the conduct of the survey of ex-patients viz ;

- addressing the critical need for information provision in the areas of 'diagnosis' and 'proposed treatment'.
- enabling patients to give 'informed consent' to the conduct of medical procedures.
- making patients aware of their rights as 'citizens' and as 'consumers' of health services.
- facilitating the education of patients about disease and causation of sickness and the 'two-way' exchange of information between Balanda and Yolŋu medical knowledge.
- facilitating the 'two-way' exchange of information about appropriate health care (including assistance to escorts in better understanding the different dimensions of their role as carers).
- employment of more Yolŋu within the hospital system.
- provision of support to Yolŋu employees in an alien environment.
- assist in the training and retention of Yolŋu staff at GDH.
- facilitating the introductory and elementary language learning needs of Balanda staff within a planned program approach, as well as helping to facilitate their spontaneous acquisition of some key language terms.
- Assist Balanda staff with their enquiries concerning Yolŋu cultural requirements and facilitate their on-going learning in this area.

The employment of Yolŋu staff within the hospital system, while it is considered desirable by both Balanda and Yolŋu alike, needs careful planning and adequate budgetary provision if it is to succeed and be sustainable in the longer term.

Consideration needs to be given to :-

- catering for the needs of male and female patients
- recognising that there are natural limits to the range of other Yolŋu persons that any one Yolŋu person is able to freely communicate with, due to Yolŋu rom and specific kinship constraints. This includes relationships of respect for elders, mother's-in-law, 'brother-sister' relationships, elder siblings etc.
- allowing for leave of absence due to bereavement and other cultural requirements or family commitments.

For the above reasons, a pool of from four to six Yolŋu Matha speakers would need to be employed / available on a part-time basis, although those on duty at any one time would rarely be more than two or three.

The person chosen for the position of health educator, as well as being knowledgeable concerning health matters in general, needs to possess a strong grounding in cross-cultural education methodology. They also need Yolŋu Matha speaking skills of a level which will allow the majority of their conversations with Yolŋu to be conducted in Yolŋu Matha. In addition they need to possess a strong commitment to on-going language learning and to fostering the discovery and development of terminology in Yolŋu Matha which can adequately convey the accurate transmission of medical knowledge to their Yolŋu co-workers, and subsequently to Yolŋu patients. As this is a specialist position, consideration would also need to be given to adequately covering for their absence from work due to holidays and other family commitments.

7.2 Escorts

Recognised by THS as an essential component in the care of patients under the age of 16 years, escorts are also an essential component of caring provision for elderly patients and for those with low English Proficiency. This is especially so in the absence of any language service provision. The importance of their multi-faceted role in aiding treatment, facilitating recovery and reducing the incidence of patients absconding, demands that adequate provision be made for their presence within the hospital environment.

Recommendation 2
That an escort accompany all elderly patients (i.e. those over 60 yrs).

Recommendation 3
That the current policy / practice for escorts to accompany all first-time and teenage antenatal patients when sent in to await confinement be continued.

Recommendation 4
That, while awaiting the provision of formal communication / language services by THS, the expectations of THS staff concerning the role of escorts be revised to incorporate a realistic assessment of the language difficulties commonly faced by both patients and escorts.

7.3 Yolŋu Rom

Recommendation 5
Attendance at Cultural Awareness Workshops run in the East Arnhem region be compulsory for all medical staff, whether short term or longer term employees, for all nurses employed for more than 3 months and for all other longer term staff.

Recommendation 6
Negotiate with appropriate agencies and cross-cultural training providers for the provision of additional 'health-issues' and skills-based communication workshops, for staff who have already attended an initial Cultural Awareness workshop relevant to the East Arnhem region.

7.4 Religious Beliefs

As shown in the survey, belief in God is an issue of great significance in the lives of many Yolŋu patients and also has a number of implications for their health and well-being. There is an expectation from most Yolŋu patients that in addition to the need for Balanda staff to recognise Yolŋu rom, they should also recognise God's power to bring about healing. At the very least there is also an expectation that Balanda staff show an open acceptance of Yolŋu expressions of their belief in God. A number of patients expressed their desire to be able to listen to christian music (played to all the rooms).
Another suggested the need for the presence of a chaplain who was able to converse with patients in Yolŋu Matha.

Despite one's own beliefs, there is clearly the potential for a patient's faith in God to bring about beneficial results, to lessen their fears and also to relate better to those staff who are prepared to listen and to talk with them about their belief in God, thus assisting the flow of communication and increasing the probability of greater compliance with treatment regimes etc.

Recommendation 7
A variety of cassette tapes of christian music (all recorded in Yolŋu Matha) be purchased by THS to be played in the ward at suitable times. THS to contact Bible Translation Centre at Galiwin'ku to negotiate that supply.

It is vital that Yolŋu Matha (and perhaps also Anindilyakwa and/or Nunggubuyu language) is used on the recordings, because this will have the added effect of creating a familiar environment for Aboriginal patients (i.e. it is what many people listen to back in their homes, especially when they are sick).

7.5 Dealing with Drunks

Balanda hospital employees and Yolŋu patients similarly acknowledge that the presence of drunks (specifically 'intoxicated Yolŋu persons') around the hospital environs, is not conducive to assisting Yolŋu patients to feel relaxed and safe. The main cause for concern from the perspective of Yolŋu patients is the 'humbug' that they receive regarding requests for money and the arguments / altercations that could possibly eventuate from an insistent drunk who will not take 'no' for an answer. In addition, escorts may also be 'humbugged' for money when shopping for the patient or withdrawing money from the bank.

It is acknowledged that there have been significant improvements made in dealing with this problem, especially in regard to patients' feelings of personal safety. One of the key measures taken by the hospital administration has been establishing a routine for the locking of doors at 6 pm. Another strategic measure of great importance has been the banning of card schools in the hospital environs. Not only is the absence of such 'entertainment' a useful deterrent for drunks, but it also adds to the long-term quality of life and well-being experienced by Aboriginal patients who are able to return to their communities 'debt free'.

Recommendation 8
That THS explore strategies to enable the conduct of shopping or banking trips for patients who are physically unable to do so, or for those who are intimidated by the presence of 'drunks'.

8. CONCLUSION

Since Janice Reid conducted her research at Yirrkala 25 years ago concerning the attitudes of Yolŋu towards hospitalisation, there have been significant improvements in the quality of physical care provided. From a Yolŋu perspective, positive changes include the increased provision of escorts, and changes observed in the attitudes of staff towards Yolŋu people and culture.

The hospital system has shown itself to be dedicated to providing a "safe and caring environment" for its patients. It has allocated resources to ensure the presence of adequate numbers of staff for cleaning, food preparation, and ward orderlies, as well as the essential provision of professionally trained medical and nursing staff (including the training of student doctors). However it has failed its patients badly in the area of providing for their basic communication needs (as per THS Patient Charter, p 12) "*to be given a clear explanation of proposed treatment, including material risks and alternative medical treatment*".

The questions that arise from this concern the alarming emergence of a wide variety of lifestyle diseases and other preventable conditions for which hospitalised patients are treated, only to re-visit hospital at some later date with the same condition. It is especially disconcerting for both staff and patients when a 'revolving door syndrome' emerges in the treatment of any one patient or members of the same family which could have been prevented 'if the message had got through'. Conversely the Yolŋu patient, from their totally different world view, wonders why the Balanda doctors with all their knowledge and powerful medicines were unwilling to cure their sickness. They do not see the limits of medical science (i.e. what doctors can reasonably be expected to do and not do), because they grew up in a different culture with a different ontological frame of reference.

Unlike Reid's findings of 25 years ago, where GDH was seen as 'curing ……. not caring', the situation now appears to have changed to one of *'caring …… not curing'*. While the standard of medical treatment has clearly improved with better technology and more highly trained staff, many of the medical conditions with which patients present cannot be cured, they can only be managed. Unless some significant changes are made in regard to language services provision, both within the hospital system and also within communities at the local clinics, overall patient outcomes will not improve they will only get worse, because the root causes of many preventable diseases are not being addressed.

Appendix 1

GLOSSARY OF KEY TERMS

Yolŋu - An indigenous person of North-East Arnhem Land.

Balanda - Non-Aboriginal persons of european origin.

Yolŋu Matha – The generic term used to describe the languages /dialects spoken by the Yolŋu people of North-East Arnhem Land. All Yolŋu grow up in a multi-lingual home environment and almost all speak several dialects with good proficiency. These dialects are generally mutually intelligible except perhaps for some of the languages spoken by persons from the western borders of the Yolŋu region. English is for most people a fourth, fifth or sixth language and is therefore 'foreign', encompassing many thought forms and a world view that is alien to the way many Yolŋu see the world.

Yolŋu rom - Refers to the rules, laws and normative behaviour adopted by Yolŋu people in everyday and ceremonial life. It could also be used to refer in general to Yolŋu culture and the cultural understandings and knowledge that Yolŋu possess concerning the world around them.

galka - A sorcerer. Sorcery is illegal by traditional law and so when it is practised, is always done in secret. The sorcerer is believed to possess superhuman powers and is capable of inflicting harm or death on his enemies or on any unsuspecting person. Fear of galka is endemic in Yolŋu communities to the extent that practically all deaths are now assumed to be caused by the action of sorcery. (See ARDS Inc. Information Paper No. 4)

marrŋgitj - A traditional doctor / healer.

mangimangi - A tool used by a galka to conduct certain forms of sorcery and which Yolŋu are very fearful of. It is illegal to possess in Balanda law and Yolŋu law.

gurraŋay matha - The intellectual language which Yolŋu traditionally used to converse about law, politics, economics, commerce, philosophy, religion and other intellectual disciplines. Nowadays many of these terms are known only by older persons who are well-versed in law and Yolŋu ceremonial life.

Appendix 2

SUMMARY OF RESULTS OF PATIENT SURVEY conducted for THS – East Arnhem by ARDS Inc. May 1977.

Context for Interview
Patients were encouraged to talk informally about their hospital experience, to share their perceptions and feelings and to express their concerns.

Survey Group Characteristics
A total of 45 people were interviewed at GDH (29 Yolŋu speakers, 12 non-Yolŋu and 4 Balanda). Gender 36 female, 9 male. Age cohorts 6 = > 50 yrs, 24 = 30-50 yrs, 15 = 18-30 yrs. Status : 31 patients, 12 escorts, 2 outpatients.

FINDINGS
Explanations About Diagnosis and Treatment
Area of primary concern for Aboriginal patients. All Balanda patients expressed satisfaction. Most Aboriginal patients expressed dissatisfaction – only 8 interviews indicated satisfaction. A typical comment / concern expressed *"They just say the name of the sickness, but not the story behind it."*

Quality of Care
The feature of patients' hospitalisation experience that received greatest number of positive comments from patients.

Feelings of Homesickness / Loneliness
Some Yolŋu patients from Milingimbi and Ramingining, as well as all patients from Numbulwar, Maningrida and Groote Is felt that Gove was too far away from family. Patients familiar with hospitals were more at ease in the hospital environment.

Respect for Patient
Most acknowledged that hospital staff treated them with respect and that Balanda and Yolŋu patients were treated equally. 5 interviews documented cases where particular staff had acted in ways that were contrary to the actions of other staff and had caused offence to Aboriginal patients.

Culturally Appropriate Behaviour and Understanding
Strong agreement amongst Aboriginal patients that most staff were ignorant of Aboriginal cultural customs.

Interpreters
Although not provided by THS, most agreed it would be of assistance to have an interpreter present.

Food
Few complaints - basically not a major issue for people as pre-occupied with other concerns.

Researcher Observations
Observations were made about what patients tended to 'talk about' (as detailed above) and 'not talk about' (ambivalence about being in hospital, sightings of spirits, fear of sorcery, views about the source / origins of sickness).

Conclusion
The survey demonstrated the commitment of THS to the provision of quality health care to all patients irrespective of their ethnicity, while also highlighting the chronic lack of information provision to Aboriginal patients regarding diagnosis and treatment.

BIBLIOGRAPHY

ARDS Inc. – Galka Djäma : Sorcery and its Increasing Use. Information Paper No. 4 April 1998.

Byrnes, D & Ward, J – The problems of hospitalisation for Aboriginal children. The Lamp, Feb 1977 v 34 (Ab & Is Health Work J 1996 Jan-Feb).

Carter, E. & Bartlett, B. – Letter in response to 'Long Way from my country – Aboriginal patients in hospital'. Med J Aust 1991; 156:350.

Coulehan, K "Keeping Company" in Sickness and in Health : Yolngu from Northeast Arnhem Land and Medical Related Transience and Migration to Darwin. Aboriginal Health: Social and Cultural Transitions Conference - NTU Darwin Sept 1995 ed. G. Robinson NTU Press 1996 : 214-22.

Devitt, J & McMasters, A Living on Medicine : A Cultural Study of End-stage Renal Disease among Aboriginal People. Alice Springs : IAD Press, 1998.

Eckermann, A et.al. Binaŋ Goonj : Bridging Cultures in Aboriginal Health. Uni of New England, 1992.

Fitzpatrick, J.M. Obstetric health services in Far North Queensland : is choice an option ? Aust Jnl of Pub Health v19 no.6 1995 580-588.

Kemp, K. Cross Cultural communication in the Intensive Care Unit : research issues. CARPA Newsletter no. 27 March 1998 19-24.

Kildea, S. "And the women said……" - Reporting on Birthing Services for Aboriginal Women from Remote Top End Communities. Women's Health Strategy Unit, THS 1999.

Muir, I. Making It Better : Evaluation of the Effectiveness of Support for Aboriginal Health Workers Employed at Royal Darwin Hospital – THS 1999.

Paul, D. It's Not As Easy As Just Walking In The Door : Interpretations of Indigenous People's Access to Health Care New Doctor Summer 1999 13-15

Reid, J. eds. Body, land and spirit : health and healing in Aboriginal society. St Lucia : UQ Press 1984

Reid, J. Sorcerers and healing spirits : continuity and change in an Aboriginal medical system, Canberra : ANU Press 1983.

Reid, J. & Dhamarrandji, B. Curing, not Caring: why Aboriginal Patients Abscond. New Doctor Vol 8:27 1978

Senior, K Potential domains of Quality of Life in Two Urban Aboriginal Communities NARU – ANU Darwin 1999. (unpublished)

Taylor, K Aboriginal Health Workers at Alice Springs Hospital : A Pilot Project to Evaluate Alternative Models of Practice for Aboriginal Health Workers - THS 1997.

Territory Health Services – Patient Assistance Travel Scheme (PATS) Procedures Darwin, THS-Acute & Specialist Care Services, Jan 1998.

Territory Health Services – Northern Territory Hospital System Patient Charter : What you can expect from the Public Hospital System, THS-Acute & Specialist Care Services, 1998.

Watson, M.L. The Communication Problems of Tribal Aboriginal Women in the Maternity Ward. (manuscript : submitted in partial fulfilment of requirements for Grad Dip in Teaching English as a Second Language) Darwin, DIT 1987.