HEALTH-SEEKING BEHAVIOUR AMONG PARENTS IN KOTA BHARU KELANTAN:

A MODEL FROM LUMBAR PUNCTURE STUDY.

BY

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ACKNOWLEDGEMENTS ii

TABLES OF CONTENTS iii

LIST OF TABLES vi

LIST OF FIGURES vii

ABBREVIATIONS viii

ABSTRAK ix

ABSTRACT xiii

MAP OF MALAYSIA 1

1.0. INTRODUCTION 2

1.1.Background

1.2.Literature reviews

1.2.1.Health- seeking behaviour among parents worldwide

1.2.2.Local taboos and folklores

1.2.3.Lumbar puncture

1.2.4.Dilemma of lumbar puncture in Malaysia

2.0. OBJECTIVES 15

3.0. METHODOLOGY 16

3.1.Calculation of sample size

3.2. Definition

3.3. Statistical analysis

4.0. RESULTS **23**

4.1. Demographic

4.2. Knowledge

4.3. Respondents' sources of information on lumbar puncture.

4.4. Level of education and source of information

4.5. Rate of refusal

4.6. Reasons for allowing lumbar puncture done in their first-degree relatives.

4.7. Complications perceived by family members

4.8. Meningitis

4.9. Decision makers

5.0. DISCUSSIONS **45**

6.0. CONCLUSIONS **56**

7.0. LIMITATIONS **58**

8.0. RECOMMENDATIONS **60**

9. REFERENCES **61**

10. APPENDIX 1 69

1.Data collection sheet.

List of tables. **page**

Table 1. Purposes of lumbar puncture 27

Table 2. Reasons given by respondents why lumbar puncture is a dangerous Procedures 28

Table 3. Different means of score within different level of education 30

Table 4. Different means of score between different income groups 31

Table 5. Respondent sources of information 33

Table 6. Level of education and source of information. 34

Table 7. Gender. 36

Table 8. Age. 36

Table 9. Presence of extended family members. 37

Table 10. Education level. 37

Table 11. Income. 38

Table 12. Score of knowledge. 38

Table 13. History of LP done in the family members. 39

Table 14. Multivariate analysis for factors that influence the decision making for factors that influence the decision making for LP. 40

Table 15. Complications perceived by respondents. 42

Table 16. Answers given regarding knowledge on meningitis. 43

Table 17. Pattern of refusal on LP and source of decision making 22 respondents with history of LP refusal in their families. 44

List of figures

Figure 1.Age distribution

Figure 2. Percentage of respondents who have heard about lumbar puncture

Figure 3. Score of knowledge.

List of abbreviations

CSF	Cerebrospinal fluid
HUSM	Hospital Universiti Sains Malaysia
LP	Lumbar puncture
RM	Ringgit Malaysia
Std Err	Standard error

ABSTRAK

Pengenalan:

Faktor sosial banyak memainkan peranan penting dalam mempengaruhi ibubapa dalam membuat keputusan dalam perawatan yang diambil.Di sini sikap terhadap perawatan contohnya didalam pengambilan air tulang belakang di kalangan masyarakat ini telah dikaji.Pengambilan air tulang belakang merupakan satu cara terpenting untuk mendapatkan diagnosis penyakit radang otak atau meningitis. Ia juga penting untuk rawatan penyakit leukemia. Pakar perubatan kanak-kanak di seluruh Malaysia mempunyai pengalaman yang hampir sama mengenai penolakkan terhadap ujian pengambilan air tulang belakang(Deng et al,1994.Ling SG,2000). Dari pengalaman kami, ramai ibubapa mempunyai perasaan takut dan keberatan untuk membenarkan ujian ini daripada dijalankan. Kajian ini di jalankan untuk mengetahui tentang sikap terhadap perawatan(health-seeking behaviour) dikalangan komuniti di Daerah Kota Bharu, Kelantan dan pengaruhnya kepada masyarakat umum.Ia juga termasuk persepsi masyarakat terhadap penyakit dan rawatan.Ini kerana kita memerlukan bukti untuk memberikan perkhidmatan yang berkesan kepada masyarakat. . Kami berharap kajian ini dapat membantu kami dalam memahami faktor persekitaran serta dapat memberikan rawatan dan kaunseling yang sewajarnya semasa merawat pesakit dan seterusnya mengurang kadar penolakkan terhadap ujian ini oleh masyarakat umum.

Objektif

Kami ingin mengkaji sebab-sebab yang mempengaruhi keputusan perawatan khususnya terhadap sikap penolakkan ujian ini dan sumber-sumber maklumat mereka. Faktor-faktor yang menyebabkan kadar penolakkan yang tinggi juga di kaji. Disamping itu kefahaman –kefahaman yang salah mengenai ujian ini juga diteliti.

Metodologi:

Satu kajian soalselidik telah dilakukan melalui telefon di daerah Kota Bharu, Kelantan.Kesemua nombor-nombor telefon number di daerah Kota Bharu yang diperolehi dari Jabatan Telekom Kelantan telah dimasukkan kedalam komputer dan 500 nombor telah dipilih secara rawak. Dari jumlah ini kami telah mengambil seramai 390 peserta. Kajian ini dijalankan dari Januari 2001 ke Julai 2001. Data-data mengenai tahap pelajaran, jumlah pendapatan, pengetahuan asas mengenai pengambilan air tulang belakang dan penyakit radang otak, pendapatan, punca pengetahuan dan juga kehadiran ahli keluarga yang telah menjalani ujian ini telah diambil.

Keputusan:

Penduduk di Daerah Kota Bharu, Kelantan mempunyai tahap penolakan yang agak tinggi terhadap ujian pengambilan air tulang belakang. Kadar penolakan adalah sebanyak 42.9%. Majoriti kaum yang di kaji adalah dari keturunan Melayu.Seramai 80.8% menyatakan sebab penolakkan ialah kerana mereka merasakan uijan ini adalah merbahaya. Sebab-sebab mengapa ia merbahaya termasuk mereka takut ia akan mengakibatkan kelumpuhan dan boleh mengakibatkan kematian.

Faktor penting yang mempegaruhi keputusan untuk menolak ujian ini adalah kehadiran ahli keluarga terdekat yang tinggal bersama iaitu nenek, datuk, ibu dan bapa saudara (OR-0.44). Pengetahuan asas yang tinggi mengenai pengambilan air tulang belakang adalah faktor utama yang dapat mempengaruhi orang ramai untuk menerima ujian ini (OR-2.85) .

Pengetahuan asas yang tinggi mengenai pengambilan air tulang belakang didapati dalam golongan yang mempunyai pendapatan yang tinggi, tahap pengajian yang tinggi dan juga dikalangan yang mempunyai ahli keluarga yang pernah menjalani ujian.

Kesimpulan:

Jumlah penduduk yang tidak membenarkan pengambilan air tulang belakang adalah tinggi iaitu sebanyak 42.9% . Kami juga mendapati bahawa masyarakat di Daerah Kota Bharu, Kelantan mempunyai persepsi yang buruk terhadap pengambilan air tulang belakang. Sumber sumber utama untuk mendapatkan maklumat ialah dari kawan-kawan dan ahli keluarga sekaligus merumuskan bahawa faktor keluarga memainkan peranan penting didalam membuat keputusan terhadap perawatan.

Kami mencadangkan supaya pihak Kementerian Kesihatan Malaysia dapat memberikan tumpuan khusus kepada soal pendidikan untuk semua anggota masyarakat demi untuk merubah persepsi yang salah dikalangan mereka terhadap ujian ini.

ABSTRACT.

Introduction:

Health-seeking behaviour is influenced by many factors. A peculiar health-seeking behaviour seen in this part of the world is high refusal rate towards lumbar puncture. Lumbar puncture is used for diagnostic and therapeutic procedures i.e. meningitis and leukaemia. However, many parents in Malaysia are aversed to lumbar puncture, as they believed it can cause harmful effects. These misconceptions and myths lead to great proportion of parents to refuse lumbar puncture in Malaysia (Deng et al, 1994 and Ling SG, 2000). Hence there is a need to look at this issue for further intervention. We believe it is important to have the appropriate evidence to deal with this issue. Household behaviour regarding perception on the disease and methods of treatment were looked at in this study.

Objectives:

Our main objective was to look at the health-seeking behaviour and in particular the basis of refusal for lumbar puncture in this population. In addition, the misconception and main source of information were also described.

Methodology:

This is a cross-sectional descriptive study, conducted by telephone interviews by the main author. The telephone numbers were obtained from the Telecom Department and were subsequently randomized. A total of 390 respondents were recruited into the study. The duration of study was from January 2001 to July 2001. Relevant data including level of education, income, basic knowledge regarding lumbar puncture and meningitis, perceptions, source of information and history of exposure to lumbar puncture in the immediate family members were obtained.

Results:

The refusal rate of lumbar puncture among the Malay ethnic group is high. This study showed a refusal rate of 42.9%. Reasons for refusal were mistaken belief that lumbar puncture is a dangerous procedure. This was reported by 80.8%of the respondents. Fears of paralysis and fear that the child might die from the procedure were the most often quoted perceptions.

A higher score of knowledge on LP is significantly associated with a chance of consent (OR-2.85), while the presence of extended family members is significantly associated with less likely chance of consent for the procedure (OR-0.44).

Higher scores of knowledge were significantly found in the higher income, higher level of education and in the group who has a history of lumbar puncture in the family..

Conclusion

The proportion of refusal for lumbar puncture in the population of Kota Bharu is high (42.9%). Despite a number of hospital-based studies there is no community-based study done in other places for comparison. Population in Kota Bharu, Kelantan had a very poor perception about lumbar puncture. Majority of them obtained their information from friends and relatives.

We recommend to the Ministry of Health that a continuous education with a wider coverage is important in changing the perception of the society on lumbar puncture which is then translated into their inappropriate health –seeking behaviour .The ministry should target all levels of society when they disperse the knowledge regarding lumbar puncture.

Map of Malaysia

INTRODUCTION

Background

Kelantan Darul Naim

Kelantan is one of the thirteen states in Malaysia, situated in the northeastern corner of Peninsular Malaysia. It has an area of 14,929 square km. The population of Kelantan was estimated to be 1,484,100 (Vital statistics Malaysia 1998). About 90% of the population live in the rural areas mostly fishermen and farmers. The Malays form the main ethnic group (92.9%) of the population, Chinese (5.4%), Indian (0.7%) and others (0.9%). Kelantan consists of ten districts namely Kota Bharu (the state capital), Bachok, Machang, Pasir Mas, Pasir Putih, Tanah Merah, Tumpat, Kuala Krai, Jeli and Gua Musang.

The doctor to population ratio is 1:2153(Social Statistic Bulletin 1996). Medical services are available to all and are free to those who cannot afford to pay. In 1995, Preliminary Study for Health Facility Master Plan found that there were three hundred seventy six health clinics in Kelantan. Two hundred forty eight were government clinics whereas one hundred and twenty six were private clinics. Two are non-governmental clinics. The ratio of population to health facility in Kelantan was 2,714 people to one health facility, which is among the highest ratio among thirteen states in Malaysia. As with the rest of Malaysia, the medical services are provided through health centres and General hospitals and are mostly free- of- charge.

Patients requiring specialized services are referred to either Kota Bharu Hospital (HKB) or Hospital Universiti Sains Malaysia (HUSM) situated within six kilometers of each other.

The standard of child health is not uniform throughout the country. The perinatal (12.6/1,000 lives birth), infant (10.9/1,000 lives birth), neonatal (5.9/1,000 lives birth) and toddler mortality rates (1.3/1,000 lives birth) of poorer state like Kelantan is higher than the national average and those of Selangor and Penang. (Technical Report of the Director-General of Health, Malaysia, 1996. Ministry of Health Malaysia).

The education system in Kelantan follows the education system for the whole of Malaysia. Formal learning starts at the age of seven years and lasts for 6 years. This is followed by secondary school education for another 5 years. Subsequently they will attend tertiary education at the university or they can join colleges for diploma or degree programme. Some may attend pre-university programme before they will be accepted into a university.

Literacy rate in Malaysia is more than 80% compared to 70% in Kelantan (HassanH.1999).

In 1997 the mean monthly gross household income for Malaysia was RM 2606 compared to Kelantan which was only RM 1249 (Mid-term review of the seventh Malaysia plan.1997). We considered those with an income of less than RM1000 to be in the lower socio-economic group. Kelantan has the highest poverty rate

that is 19.2%. The poverty rate in Kelantan is three times higher compared to the poverty rate for the whole of Malaysia. The total household income for Kelantan is fifty percent lower compared total household income for Malaysia (Hassan H, 1999).

There is a discernable difference between the demography, economy, politics and culture of Kelantan compared to the other states of Peninsular Malaysia. Kelantanese culture is complex and it was one of the earliest areas in Malaysia to embrace Islam. Kelantan is recognized as one of the most conservative areas in the country and is often considered a centre of Islamic culture. At the same time traditional beliefs are heavily influenced by mysticism (Firth R.1974). Historical Thai domination (Wyatt DK.1974) of the region is also reflected in secular cultural expression. The complexity of the culture is increased by recent influence of western materialism and technology.

The utilization of traditional medicine is widespread throughout Kelantan. Increasing literacy and wealth does not appear to have significantly affected the use of traditional healers (bomohs). Bomohs practice their art in various ways from the use of holy water to herbs and massage. One of the most widely supported and apparently successful applications of traditional healing is that of bonesetting. Although Islamic teaching does not support the method used by traditional healers, the practice survives due to continued support by population and the adaptation of methods to incorporate aspects of Islam such as 'Doa' (Firth R.1974).

Majority of the Kelantanese population are Malays with Islam as their main religion. We believe a significant number of people in Kelantan still have a very strong faith in traditional medicine leading to delay in seeking treatment. Many are averse to lumbar puncture, as they believe LP could cause paralysis, impotence, and mental retardation. Some even believe that LP lead to depletion of CSF thus cause dryness of the brain and damaging it (Malik AS.2000). A small number of people also believed that lumbar puncture is prohibited on religious basis. However the truth of these remain obscure. Some of the people in Kelantan believe that a lumbar puncture cause continuous damage to the patient and they will become sick until adulthood (Malik AS.2000). Example of other misconceptions is that the cerebrospinal fluid is taken by draining it out from the spine. The above belief lead to a significant number of our patients to refuse lumbar puncture, affecting the health-seeking behaviour significantly.

Health- seeking behaviour among parents worldwide

Health-seeking behaviour differs from country to country and races. Factors such as socio-economic status, cultural factors, education level, distance from the hospital, acceptability of the hospital services, demography, and the resources and management of the hospital.

Demographic factors, such as the age of the community will affect hospital morbidity and utilization patterns (Llewelyn-Davies & MacAuley.1996). The same author found that the level of hospital utilization is likely to be higher in urban areas as hospital is a familiar part of the urban environment.

The extent to which economic factors influence an individual's decision to go to hospital is related to the system of payment for services. Studies in Nigeria (Okafor.1983) and Ethiopia (Yohannes & Streatfield.1988) showed that the demand for hospitalization increases in a group of people who have higher income and education, even if alternative or traditional medicine is available.

In developing countries, cultural factors are significant as there are usually wide ranges of alternative medical therapies available. These alternative therapies have always been accepted and easily accessible to the community. Hospitals, on the other hand, are frequently seen as a new concept that as yet may not be fully accepted by all sectors of community (Llwelyn-Davies at al.1966, Tanashi.1978).

Patient satisfaction is a major factor affecting health-seeking behaviour. Failure to provide the patient with adequate information affects the subsequent health-seeking behaviour. (Linder P.1982). Inaccurate explanations will lead to inappropriate dissemination of knowledge among community members.

In Kelantan, traditional medicine is still important in the community. Traditional healers and spiritists (both called bomoh) and traditional midwives (bidan) play very important roles in Kelantan society (Wyatt DK.1974). Of the 600 members of the traditional healers association in Malaysia, 200 are from Kelantan.

In Malaysia, a study done by Roslani et al (1989) showed 52% patient had first sought treatment from traditional healers before coming to hospitals. Roslani et

al (1989) also showed the tendency to seek multiple forms of treatment simultaneously due to lack of confidence with single mode of therapy.

Local Taboos and Folklores

In Kelantan, traditional medicine is still important. Malays in Kelantan believe in a general simplistic conceptual framework when it comes to healing processes. These belief can be crudely translated as knowledge, revelation, medicine, soul spirit and superhuman power.

They also believe in the concept of hot versus cold and the effects of these on the body and health (Konare et al.1988) in a manner similar to traditional Chinese belief of 'Ying' and 'Yang'. The community structure in Kelantan is closely linked with a clear hierarchy and authority of the elders. Confidential medical information is easily and willingly shared with members of the community. As such, the belief on procedures such as lumbar puncture has been circulated in a negative way that has jeopardized management of neurological disease in this state. These local taboos and folklores must be studied in very serious manners as part of the effort to deliver the most effective health care to the population.

Lumbar puncture

Quincke first introduced lumbar puncture in 1800 for the examination of the cerebrospinal fluid in the diagnosis of neurological disease. A lumbar puncture (LP) is the insertion of a needle into the fluid within the spinal canal. It is termed a "lumbar puncture" because the needle goes into the lumbar portion of the back and into the subarachnoid space at the lumbar level (L3-4, L5-6). The other name for a lumbar puncture includes spinal tap, spinal puncture, thecal puncture and rachiocentesis. An LP is most commonly done for diagnostic purposes, namely to obtain the cerebrospinal fluid for examination purposes.

This procedure may also include measurement of cerebrospinal fluid (CSF) fluid pressure, withdrawal of CSF for testing or instillation of therapeutic agent. The role of lumbar puncture in the diagnosis of meningitis is well established. (McCarran et al 1996). The table below shows the other indications for lumbar puncture.

Table 1:Indications of lumbar puncture

	Diagnostic	Therapeutic
Indications For Lumbar Puncture	.Meningitis .CNS neoplasia .Lead encephalopathy .Pseudotumourcerebri .Intracranial haemorrhage (neonates)	Leukaemia Lymphoma Refractory infection (e.g. fungal) Pseudotumourcerebri

Scanty data is available from other countries regarding lumbar puncture refusal. In a study done in The United States on Lyme's disease, only one (5%) out of twenty patients refused lumbar puncture (Jacobson DM, 1991). Another Danish study on isolated optic neuritis showed that 5 out of 68(7%) patients refused LP (Frederiksen JL, 1992).

The seriousness of bacterial meningitis in paediatric mandates a rapid and more accurate diagnosis, available only through lumbar puncture. Bacterial meningitis remains a life threatening illness despite anti microbial therapy, with mortality in neonates of between 15-20% (Klein JO et al, 1986). Mortality beyond the neonatal period is less than 10%; however, neurological sequelae may be present in as many as 50% of the survivors. These sequelae including hearing deficits, seizures, motor impairments, learning and developmental disabilities (Klein JO et al, 1986). In a local study done by (Ismail Hussein I.H.M, 1998), 71 of 435 patients (16.7%) had Hemophilus influenza meningitis. The mortality rate was 12.5%, 30% suffered neurological sequelae. The neurological sequelae were cortical blindness and epilepsy. All of them had motor deficits and six were quadriplegic. In a study by Choo K.E et al in 1990, patients presented with pyogenic meningitis showed a mortality rate of 18.9% and neurological deficit of 54.3%. Therefore the benefits of lumbar puncture are clear. It is an essential procedure for diagnosis of a serious and potentially life threatening illness (Keith IM, 1986). Delay in the diagnosis of meningitis is a recognized risk factor for disease sequelae (Herson VC et al, 1977). In recent years it has been realized that the bacteria causing meningitis have developed resistance to antibiotics. Thus the need to perform lumbar puncture and obtain CSF fluid for culture is

necessary to confirm the bacteria causing the disease and to determine the most appropriate antibiotic. These two important reasons make lumbar puncture a vital clinical procedure in present day medicine.

There has been much debate regarding the role of lumbar puncture especially in the diagnosis of meningitis in recent years. This does not only scare the population at large but also the health professionals. Many reports have described the risk of lumbar puncture including cerebral coning, post lumbar puncture headache and epidermoid tumor (Richards PG et al, 1986). There has been a suggestion that lumbar puncture performed during bacteremia can cause meningitis (Teele et al 1981). These associations are most significant in children under one year old and have not received any initial antibiotics.

The dangers of lumbar puncture in the presence of raised intracranial pressure have also been well published (Korein J et al, 1959). A number of reported cases showed that coning will occur following lumbar puncture in raised intracranial pressure. Coning is not only due to the sudden removal of the CSF but also due to persistent leaking of the CSF through the spinal puncture. To reduce this risk, pre-lumbar puncture CT scan has been recommended in the presence of reduced level of consciousness, a history of worsening headache, focal neurological signs or papiloedema (Ballantyne et al, 1993). Recent reports, however, have suggested that even with a normal CT scan, lumbar puncture may remain unsafe (Rennick G et al, 1993). The other rare complication was hearing loss which could be permanent. Nerve roots herniation in the patient

who has spinal stenosis had also been described. This will lead to persistent backache and significant neurological symptoms (Hasegawa K et al, 1999).

The incidence of headache may be diminished by the usage of small-gauge needles (20 gauge or less) or by placing the patient in a prone position for several hours after the procedures (Brocker RJ, 1958).

Other complications include painful paresthesias that may occur in as many as 13% of patient but ordinarily disappear within 1 year. Some patients have occasionally reported leg numbness or cranial nerve palsies (Vandam LD, 1960). Another potential complications of the lumbar puncture are infection such as spinal abscesses (Rifaat M et al, 1973).

Spinal haematoma can occur in patients who have bleeding disorders. However, routine bleeding profile is not necessary in-patient who did not exhibit bleeding tendency

Proper assessments by senior and competent doctors are necessary to prevent this complication. Failure to give proper explanations to patients will affect their subsequent health-seeking behaviour. Their fear is genuine as it is very difficult to predict the prevalence of this complication despite the usage of CT Scan of brain (Ajay GK.1999).

Despite the above complications, lumbar puncture is clearly indispensable in a patient who is suspected to have meningitis and malignant diseases. Most

reviews and textbooks emphasize the need for a high index of suspicion and the importance of performing a LP in any child suspected of having meningitis (unless there are specific contraindication to this procedure). In fact some of the author agreed that LP is necessary in children less than six months of age. Some argued that children less than 18 months with their first febrile seizure require LP (Rutter N et al, 1977); others have used an older cut off of two years of age (Illingworth, 1980).

Dilemma of Lumbar Puncture in Malaysia

In general, most paediatricians in Malaysia particularly in Kelantan share a common experience of having patients or their next of kins refusing lumbar puncture. This behaviour is unique and no data has been published elsewhere. A descriptive study carried out by Boey in University Malaya Medical Center, Kuala Lumpur showed that the majority of the parents who refused this procedure came from the Malay ethnic group (Boey, 2000). This also showed in a study done by Deng et al in National University Hospital of Malaysia. However, in view of the above complications that may occur, their fears may not be without basis because the risk of coning in patient with suspected meningitis who have had lumbar puncture done is about 6%(Benjamin CM et al.1988). Furthermore recent reports have tended to emphasise on the risk of lumbar puncture while paying little attention to the risk of not performing. There are many misconceptions and myths circulating in the Malay communities regarding this procedure (Deng at al and Malik AS). Both studies done by Deng et al and Ling SG, showed significant number of parents refused lumbar puncture due to the

fear of paralysis and death. These two studies showed a higher rate of refusal occurred especially among the Malay ethnic group. Another study done by Malik A.S et al also showed that the fear of paralysis was the main reason for refusal.

In our own University Hospital (HUSM), 66% of our patients who were treated for meningitis from 1995 to 2000 were diagnosed on clinical grounds alone due to difficulties arising from the refusal of lumbar puncture. (Medical Record Database, HUSM 2001). Twenty three percent of the patient gave consent for the procedure and in twelve percent of the patients; lumbar puncture was done without consent (i.e. patient who were admitted to intensive care unit). In contrast with a study done by Wahab JA et al (2000) whereby only 23% of their patients refused lumbar puncture. Throughout the five years review on meningitis in HUSM, we only manage to culture twenty cerebrospinal fluid samples. Majority of the patient who were diagnosed to have meningitis on clinical pictures will receive at least 10 days of intravenous antibiotic on an empirical basis. These will give rise to unreasonable strain to the financial resources and inappropriate utilization of manpower. The cost will be even higher if the calculations include total number of lost of working days for parents accompanying these children in the ward. Ismail Hussain I.H.M in 1998 showed out of 435 cases of meningitis that were admitted to five centres in Malaysia (Paediatric Institute, HKL; Kota Bharu Hospital, Kelantan; Sultanah Aminah, Johor; Hospital Alor Setar, Kedah; and Hospital Kuching, Sarawak), lumbar puncture were consented in 71 of the patients (16.3%). This not only led to difficulty in obtaining the data but also cause a hindrance in the management. LP

refusal has been thought to be a possible hindrance to the detection of intracranial infection in Malaysia (Sinniah M, 1989).

A descriptive study was done in Malaysia regarding the rate of refusal of lumbar puncture especially in-patients who were admitted for febrile convulsion. They found out that the percentage of refusal varies from 25% (Ling SG and Boey CC, 2000) to 54% (Malik A.S and Zabidi, 1995). Another study that was done by Deng et al showed a refusal rate of 28.6 %.

The rate of refusal was noted to be higher in the Kelantanese population (Malik A.S and Zabidi, 1995) compared to the population in Kuala Lumpur. The other alarming fact was that patients who refused LP were significantly more likely to discharge themselves from the hospital 'at their own risk' (AOR) according to the study done by Ling SG (2000) in Kuala Lumpur. Patients who discharged themselves 'AOR' following LP refusal are at great danger as the diagnosis and treatment of meningitis might be further delayed. Without lumbar puncture, we can opt to treat the patient empirically as having meningitis and provide a complete course of intravenous antibiotics. However, this may incur unnecessary prolonged hospital stay and additional costs as well as subjecting themselves to possible complication of the treatment. When a child presenting with apparent febrile convulsion is suspected to have meningitis, and the parent refused LP, the doctor is put in a very difficult position. Physician can get a court order for lumbar puncture to be done but it may lead to unnecessary aversion of community at large towards hospital and their treatments.

Other implications include the unability to make a firm diagnosis of meningitis without a cerebrospinal fluid sample. The epidemiological study of meningitis in the local set up will not be comparable with the international data.

This study was done in an attempt to seriously look at this dilemma in order to improve the health status of this community.

2.OBJECTIVES:

Primary Objective.

1) To explore the perceptions on lumbar puncture of the parents in Kota Bharu District in Kelantan (Community-based study).

Secondary Objective

1.) To determine the basis for refusal and to determine the misconceptions and reasons for refusal

3) To determine the main source of information on lumbar puncture for parents

4) To determine the main decision maker in the family.

3. METHODOLOGY

This was a cross-sectional study, conducted by telephone interviews in the district of Kota Bharu, Kelantan.This district was chosen because it is the most populated area in Kelantan where the majority of our patients came from.

All the home telephone numbers in the district of Kota Bharu were obtained from the Kota Bharu Telekom Office. A total of 25,000 telephone numbers were available. 500 numbers were chosen using computer-randomized sampling. Interviews were conducted from January 2001 until July 2001. The study was conducted every alternate day from 8.00 a.m-4.00p.m. To cater for the working group we extended the study during public holidays as well. These numbers were taken to compensate for respondents who may not be available at home and allowing for a drop out rate of 25%. This study required 384 respondents to have a power of study of 95 and confidence interval of 95%. The calculation of sample size is shown in **4.1**.

Each telephone number was contacted on three occasions. The number will not be considered, if no answer were received after 3 trials. A total of 390 respondents participated in this study. The chief investigator who speaks the same language as the local population conducted all telephone interviews.

The interviews were guided by a set of standard questionnaires. The respondents interviewed fulfilled the following inclusion criteria:

Inclusion criteria:

i) They are primary caretakers of children in the household.

ii) Age of more than 18 years old

iii) Verbal consent given.

Exclusion criteria:

i) Not the primary care taker of the children

ii) Failed to answer phone calls three times

iii) Participants who cannot converse in Bahasa Malaysia

Data collection was by telephone interview using prepared questionnaires, which was previously validated. Each interview took approximately 10 minutes. The questionnaires were given in objective manners but there were few as open-ended questions. Verbatim responses were recorded and analyzed. Please refer to Appendix 1 for questionnaire design.

The interview was conducted in Bahasa Malaysia. The requested information were:

i) Age, race, sex, marital status and level of education of the informers.

ii) Job status and income.

iii) Knowledge regarding lumbar puncture for example, basic technique of lumbar puncture and the purpose of lumbar puncture. Scores were only given to those who can give correct answer regarding lumbar puncture

iv) Source of the knowledge.

v) Perception regarding lumbar puncture.

vi) Any history of exposure to lumbar puncture in the immediate family members.

vii) Acceptance for lumbar puncture for their children.

viii) Their understanding regarding meningitis. These answers were considered correct: if they can give the cause of meningitis and/ if they can describe the complications of it. An answer that was contrary to medical practice was considered wrong.

3.1.Calculation of sample size

A formula to calculate a sample size with a power of 95% is shown below. We worked on an assumption that 50% of the population will refuse lumbar puncture (Malik et al)

$$\text{No. of sample: } \frac{Z\,(p)q}{e2} = \frac{1.96 \times 1.96 \times 0.5 \times 0.5}{(1-.95)2} = 384$$

z=constant

p=prevalence of refusal.

q=1-p

e=precision (power of study)

3.2.STATISTICAL ANALYSIS.

Statistical analysis was made using SPSS version 10 for personal computer. All categorical variables were analyzed using chi square test and Fischer exact test when indicated. Non-parametric tests (t test for two independent samples) were used for continuous variables. A p value of less than 0.05 was considered significant. The comparisons for more than two means are tested using ANOVA test. ANOVA test were used if comparison between more than two groups were done. Scheffe test was used in the post hoc ANOVA test.

3.3.DEFINITION

Respondents will be put into **exposed** group if there were history of lumbar puncture done in their first-degree relatives

Respondents who did not have any history of lumbar puncture in their family members were considered **non-exposed**

Correct answers means they were able to give the cause of meningitis and/ complications of meningitis.

Wrong answers means if they give any answer that was against medical understanding

Good score means the total score is 4.00 and above. This is an arbitrary score only.

Low level of education means those who did not attend any formal schooling or those attended only primary school.

Low socio economic group means those who're earning less than RM1000(Mean monthly income in Kelantan RM 1249 (Mid-term review of the seventh Malaysia plan 1997)

Extended Family members means presence of a grandfather or grandmother or an uncle or aunt in the family.

4.0. RESULTS.

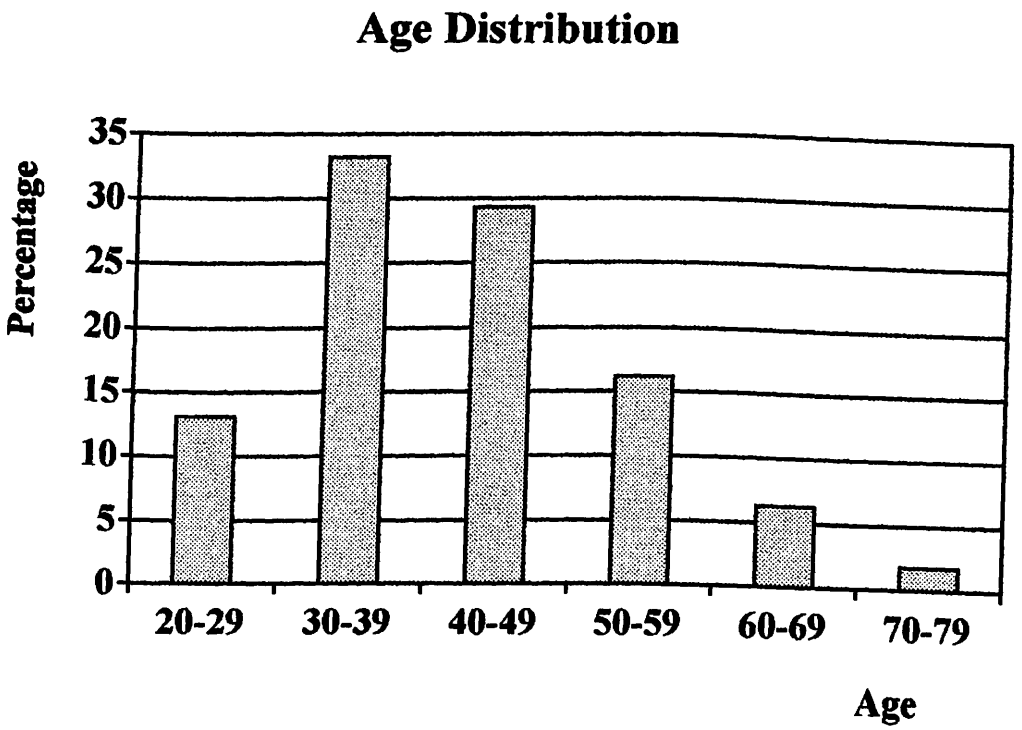
4.1.Demographic.

4.1.1. Gender.

A total of 390 respondents were included in the study. There were 263 females (67.4%) and 127(32.6%) males giving a female to male ratio of 2.07:1. Majority of the respondents were Malays, 344(88.2%) followed by Chinese 37(9.5%), Thai's 5(1.3%), Indians 3 (0.8%) and others 1(0.3%).

4.1.2. Age

Figure 1: Age distribution.



The respondents age ranges from 20 to 79 years. The median age of the respondents was 40 years of age. Mode for range of groups was in the age groups of 30 to 39 years.

4.1.3. Level of education.

Majority of our respondents had at least completed their secondary school education (51.2%). This was followed by those who had received no formal education and those who had completed at least their primary education (24.7%). Twenty-four percent (24.1%) consist of those who had received their tertiary education.

4.1.4. Employment status.

One hundred and forty three (37.4%) were not working with majority (142) were housewives (97.6%). Two hundred and thirty two (60.2%) were working either in the government sector or private companies. Those who owned their own business were also included. Ten (2.4%) of the respondents were pensioners. Five of the respondents refused to describe their type of work.