



AWARENESS AND KNOWLEDGE ABOUT THE PATIENTS' RIGHTS AMONG RESIDENTS OF KANDY DISTRICT

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ABSTRACT

Patient rights encompass legal and ethical issues in the provider-patient relationship. Charter of the patients' rights promulgated by the American Hospital Association (AHA) offers guidance and protection to patients with the statements describing the responsibilities that hospital and its' staff are bounded toward patients and their families during hospitalization. Quality of care can be delivered to the patients with the effective communication. Patient can also participate in shared decisions making relating to his/her medical care based on socio cultural environment and level of education. Hence, objectives of this research are to assess the awareness about patients' rights among the citizens of the Kandy. Sample of 200 was selected representing urban and rural areas in Kandy district and a self-administered questionnaire was used for data collection. Simple random sampling method was obtained . Questionnaire was pre validated for the content with experts' opinion. Responding percentage was 89 %. The extracted data were tabulated using "Microsoft Excel spread sheets" - 2007 package and analyzed through SPSS version 20. Chi square test was adopted. $\chi^2 = 3.84$ was considered as absolute value in $\alpha = 0.05$. Only 35.19% (Chi square value 15.69) were aware on of patients' rights, but they were not aware about the specific charter. The findings highlighted key areas of deficiencies in knowledge as "identify documents which are stated on patient right", "obtaining medical records and medical insurances", and ask about "secondary health opinions. Study results can be used to improve the quality of health care through the protection of patients' rights, with the aim of enhancing patients' satisfactions. Key words Patients' rights, legal, quality of health

INTRODUCTION



“The Universal Declaration of Human Rights (UDHR) has been instrumental in enshrining the notion of human dignity in international law, providing a legal and moral grounding for improved standards of care on the basis of our basic responsibilities towards each other as members of the “human family”, and giving important guidance on critical social, legal and ethical issues” (WHO).As it described, patient rights amendment through the UDHR with the relationship between human rights and right to health. To clarify the dilemma between the human rights and patients rights United Nations Commission on Human Rights (UNHCR) has designated a Special consideration as “Health for all”. Though many countries had amendment specific bill of charters to implement patient rights, in Sri Lankan patients’ rights are covered under UDHR.

Constitution of the Republic of South Africa (Act No. 108 of 1996) described the charter of patient rights.

Healthy and safe environment

Participation in decision-making

Access to health care- Everyone has the right of access to health care services that include:

receiving timely emergency

treatment and rehabilitation

provision for special needs

counseling without discrimination,

palliative care

a positive disposition

health information Knowledge of one’s health insurance/medical aid scheme

Choice of health services

Treated by a named health care provider

Confidentiality and privacy

Informed consent

Refusal of treatment

A second opinion

Continuity of care

Complaints about health services

BACKGROUND OF STUDY

The present study to explore “awareness patients’ rights among residents of Kandy district” is carried out on a randomly selected sample of individuals from the two communities living in Urban and Rural areas of the Kandy district. The two areas are selected because they contain a multiethnic population having different levels of education and occupations and minimize the sample bias.

PROBLEM JUSTIFICATION

Although patients’ rights are highly valued in settings of health care, studies in other countries (Emamirazavi, 2006) have shown that most people do not aware on patients’ rights. There is a gap of knowledge can be identify in between the human and patients rights. Awareness about patients rights have immense benefits to patients allowing own decision making under crucial situations, obtaining high level of patients safety and receiving highly qualitative and quantitative health care ,should be promoted among patients.



RATIONALE

It is important to the health care provider to identify the level of awareness and attitudes regarding the patients' rights in the community. Even though studies have been conducted in other countries to assess the awareness regarding patients' rights ([Manjavidze 2006](#), [Kuzeimail 2006](#)) such studies are scarce in the developing countries. Hence, my objective is to assess the awareness about patents rights in the community and also to find out whether the awareness varies between level of educational.

SIGNIFICANCE OF THE STUDY

Advantages following to the research can be summarized as access to a range of healthcare options ensures that patients are able to receive the right care at the right time, Community will have access to an array of safe, high-quality and cost-effective healthcare professionals.

LITERATURE REVIEW

Many researches followed about the "patient's rights" "with the aim of understanding the level of awareness and attitudes towards the process. Gap of knowledge can be identified while considering on research findings. [Wagner](#) (1994) researched on situations of ethical dilemmas of patients rights in "Israel "based on code of ethics in Israel. He describes nurses' role in decision making process as reporting "In this era of major advances in medicine, the nurse's role as the protector of patient rights may bring about conflicts with physicians' orders, with institutional policies, or with patients". [Emamirazavi](#)

(2006) reported the evaluation of the awareness of the patient rights in the hospital of the "Teheran]" after displaying the charter in the public and hospital setup. Finding of the research reported that more than half of the percentages do not aware on the charter of the patients' rights after the two years of displaying. But it was interesting to identify most of them were satisfied with the nursing and medical care they received. Findings conveyed the gap of the knowledge about the charter of patients' rights.

[Manjavidze](#) (2006) assessed the level of knowledge and attitudes towards the patients' rights in physicians in Georgia from the point of physicians' view. Findings of the research reviewed that during the process of surveying the respondents mostly indicate to necessity of expanded information of patients in terms of payment for medical services, information dealing with test results, diagnosis and treatment, prognosis of disease. According to physician's view, the patients are less informed that reflects in delayed visit to physician. Data from the surveyed physicians shows that one of the most significant problems is related to informed consent on medical manipulations. As it was revealed most of them did not require informed consent during their practice. [Ducinskiene](#) (2006) researched on "Awareness and practice of patient's rights law in Lithuania" and reported, the results indicate that the Lithuanian medical profession is well-informed about the patient's rights but do not always respect these rights. And they suggested his may be influenced by concomitant lack of knowledge and assertiveness in the patients they serve. These results suggest a need for awareness-



raising among patients to improve the practical implementation of the Patient's Rights Law in Lithuania thereby reducing the burden on the medical professionals in carrying the responsibility for quality assurance in health care single-handedly. Zulkifkar (1998) was carried out to research to describe the level of awareness of patients concerning their rights in Turkey. The main hypothesis was: the higher the socioeconomic and cultural level of patients, the higher is their awareness of their rights. And research findings described more than 60% of the participants were not aware about the charter of patients rights.

Klara S (1994) reported with her research on "A Patient's Right To Information: Awareness is the Key" a patient's level of awareness regarding a disease, its symptoms, and available treatment options significantly affects the quality and efficiency of treatment that a health care professional can deliver. And she also impressed the value of obtain knowledge on patients rights and how to implement them in the settings of health care. Kuzeimail (2006) researched "Patients' awareness of their rights in a developing country" in the hospital settings of Turkey. Research findings summarized the few patients knew about the regulation on patients' rights, indicating a need for extensive education of patients and healthcare professionals. Ronda G (2008) researched on medication as the patients' rights and how it implemented by health staff and research addressing the complex process of medication use in hospitals is badly needed and requires a new approach to produce valid knowledge from studies done in the field with few controls of confounding factors. Ojwang (2010)

discussed Nurses' impoliteness as an impediment to patients' rights in selected Kenyan hospitals, and reporting the gap between the knowledge and awareness on patients rights as research findings reviewed *or patients to enjoy their rights in the hospital setting, a clear definition of roles and relationships and public education on strategies of asserting their rights without intimidation are necessary. It emerges that when patients' rights are denied, patients resort to retaliation by violating the dignity of the nurses. This jeopardizes the envisaged mutual support in the nurse-patient relationship and compromises patient satisfaction.* Abekah (2010) reported in his research "Assessing the implementation of Ghana's Patient Charter" that Study findings show that the majority of patients are not aware of the existence of the Charter of those that know about it, a sizeable minority are not knowledgeable about its contents. Relative to patients, providers exhibit better awareness and content knowledge of the Patients' Charter, but on the whole are not yet carrying out their responsibilities under it. In terms of socio-demographic factors influencing awareness and knowledge of content, only education was found to be a positive correlate of awareness and knowledge.

Above studies convey the specific ideas which highlighted the importance of patients rights and the variations based on cultures .They highly emphasized how patients rights , leads to build up patients autonomy offering legal coverage, when patients are free to decide about their own health.

OBJECTIVES



To determine the level of awareness and knowledge towards the patients' rights among residents in the Kandy district

MATERIALS AND METHODS

Study area, population and units

The present study was carried out to find out the "awareness and knowledge about 'patients rights' in a randomly selected samples from the two communities (urban-Wattegama division, rural-Bogahakumbura division) Kandy district" during the period of August –December 2011. A Specific areas of the district were selected for the research due to time constraints and convenient accessibility. The sample of 100 was selected from each division using random number sampling. Total number of participants was 200. All selected participants were over 18 years of age. A Random sampling method was used

to select the sample .Sample selection was based on Inclusion and exclusion criteria. Inclusion criteria were "residents of the urban and rural from selected areas". Exclusion criteria were participants having psychiatric illnesses and participants with physical deformities (low level of hearing, blind)

Data collection and collection tools

Initially a pre test was conducted on ten participants after obtaining verbal consent. After conducting the pre test the questionnaire was amended and finalized. The finalized questionnaire consists demographical data, close ended questions .Demographical data contained with Age, Ethnicity, Gender, Monthly income, Occupation, Education Level (Up to O/L, Up to A/L, Up to Degree levels) were collected.

Close ended question contained,

- 1 Do you know about charter of patients rights?
- 2 Should you consider environmental safety and healthy while receiving treatment procedure?
- 3 Should you Participation in the process decision-making with health care provider?
- 4 Should you receive emergency care when it is needed?
- 5 Should you participate the rehabilitation process after discharge?
- 6 Is it essential to obtain special procedures with the positive approach of health staff?
- 7 Should you to discuss about palliative care before obtaining treatments?
- 8 Should you ask questions for further clarification?
- 9 Should you receive medical reports, insurances reports with the correct mentioning of treatment procedure?
10. Is it essential to specify the name of special person /institute as secondary health opinions by primary health care provider?
- 11 Should you know the name and designation of health care provider prior to obtain treatments?
12. Is it essential to receive privacy in hospital set up?
- 13 Is it essential to obtain informed consent prior to treatment procedure?
- 14 Should you think that you can refuse treatment procedures?
- 15 Should you discuss secondary treatment if the primary treatment is not improving?
16. Is it essential to receive continually of care?
- 17 Can you complain about treatments if you are not satisfied with them?



Questionnaires were distributed among residents after obtaining verbal consent. The purpose of the study was explained to the villagers. All participants were informed and convinced that Privacy and confidentiality of the provided data will be maintained. Participants were educated that data provided will use only for research purposes. Participants were asked to fill up the questionnaire. Interviews were conducted for participants who were reluctant to fill up the questionnaire. Interaction was essential in order to obtain feedback from some participants. Interaction was achieved through building up a good rapport with the participants during data collection. From the selected 200 participants 179 were positive about the research and gave their consent to participate. , 21 declined to participate in the survey. Results from pre test are not used for data analyzing purposes.

STATISTICAL ANALYSIS

Acquired Data was entered into “Microsoft Excel spread sheets” (Microsoft office 2007 package) and analyzed. Analysis was based on three variables: Gender, Education level and Age. Percentages were calculated and differences between percentages were identified through bar charts

RESULTS

From the selected sample of 200 only 179 agreed to participate in the survey. Table 1 gives a summary of the demographic profile of the 179 (89.5%) participants based on residence area (Urban, Rural) level of education (Up to grade 5, Up to

Ordinary level, Up to Advanced level, Graduate) .According to Table 1 there were even numbers of participants from urban and rural areas .In urban areas more participants had an education up to the ordinary level and the Advanced level .In rural areas participants who completed tertiary level of education were less than other groups. Number of participants who educated up to Ordinary levels were higher than others.



Table 1: Summarized demographical

Variables	Urban				Rural			
	86 (48.04%)				93 (51.95%)			
Education level	Up to grade5	Up to O/L	Up to A/L	Degree level	Up to grade5	Up to O/L	Up to A/L	Degree level
	Percentages	10.46%	38.37%	30.23%	20.93%	12.90%	45.16%	33.33%

From the extracted data results based on variables, were tabulated using “Microsoft Excel spread sheets” (Microsoft office 2007 package) and analyzed. Bar charts were used to calculate percentage differences within responses. (Figure no’s: 1-4).

Table 2: Responses for whole research sample

Q NO:	Yes%	No%
1 Do you know about charter of patients rights?	35.19	64.80



2 Should you consider environmental safety and healthy while receiving treatment procedure?	43.01	56.98
3 Should you Participation in the process decision-making with health care provider?	41.34	58.65
4 Should you receive emergency care when it is needed?	42.45	57.54
5 Should you participate the rehabilitation process after discharge?	47.48	52.51
6 Is it essential to obtain special procedures with the positive approach of health staff?	53.63	46.36
7 Should you to discuss about palliative care before obtaining treatments?	35.19	64.80
8 Should you ask questions for further clarification?	39.10	60.89
9 Should you receive medical reports, insurances reports with the correct mentioning of treatment procedure?	28.49	71.50
10. Is it essential to specify the name of special person /institute as secondary health opinions by primary health care provider?	32.96	67.03
11 Should you know the name and designation of health care provider prior to obtain treatments?	58.10	41.89
12. Is it essential to receive privacy in hospital set up?	87.70	12.29
13 Is it essential to obtain informed consent prior to treatment procedure?	77.09	22.90
14 Should you think that you can refuse treatment procedures?	41.34	58.65
15 Should you discuss secondary treatment if the primary treatment is not improving?	55.30	44.69
16. Is it essential to receive continually of care?	64.80	35.19
17 Can you complain about treatments if you are not satisfied with them?	56.42	43.57

Table 02 and figure 01 summarizes percentage differences on awareness and knowledge about the patients' rights. Percentage differences can be noted in positive and negative approaches of responses.

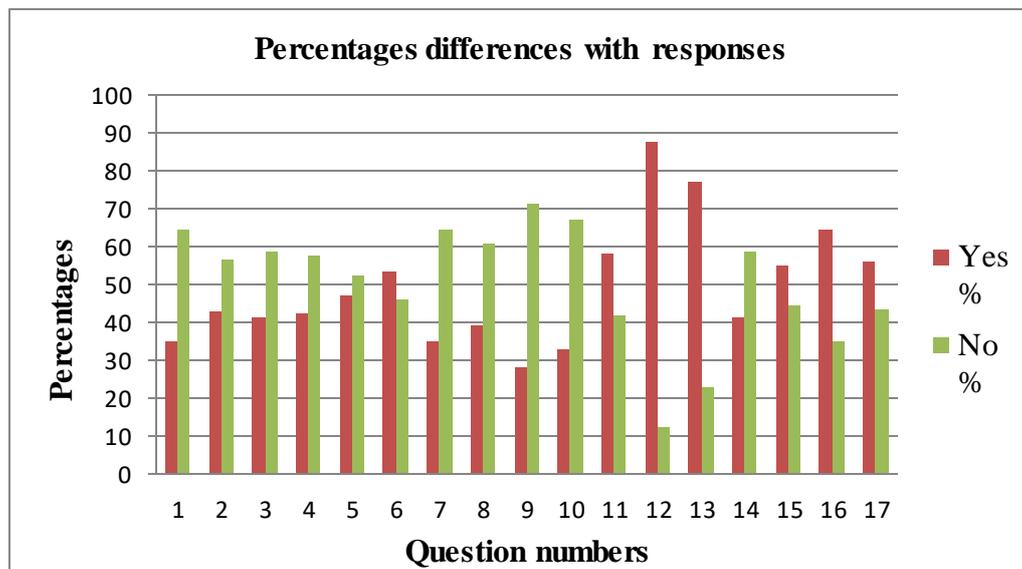


Figure 1: Percentage differences with responses for whole research sample

Less percentages of participants had vague idea about charter of patients’ rights (Percentage value is 35 % in Q1-(Do you know about charter of patients rights?). Though they were not aware about the charter of patients’ rights they had knowledge and awareness about the concepts and ideas. Safety of environment was not much considered when receiving the treatment regimens. Only 58% of participants join the process of decision making with the health care provider. Participants consider about emergency care when it is needed and they hadn’t positive idea about the process of rehabilitation. Special procedures and specific treatments were highly valued by the participants and they positive approach towards it. Participants hadn’t idea about the caring for the death persons (palliative care), and they had presented with idea caring for the death person is not essential. Participants were not familiar with asking questions and

obtaining further clarifications from health staff as the percentage is 60%.They were not associated with obtaining medical insurances forms and validity of health insurances. Processes of heath insurances were not familiar with the Sri Lankans.70% of participants believed that they had to notify the name of the secondary health care provider ‘s by the primary health care staff, and they are depended on the health staff in the process of decision making process.People satisfied with the level of privacy they are receiving present, and only 12% of them were not satisfied with the level of privacy. Though they were aware about the informed consent (77%) the knowledge about the process of consent was not clear and refusal of treatment if they don’t accept it was not popular. Sri Lankans highly concern about continuity of the treatment process and (64%) and secondary treatment options (55%).

Table 3: Responses among urban and rural participants



Q NO:	Urban (Yes %)	Rural (Yes %)
1 Do you know about charter of patients rights?	37.20	33.33
2 Should you consider environmental safety and healthy while receiving treatment procedure?	50	36.55
3 Should you Participation in the process decision-making with health care provider?	46.51	36.55
4 Should you receive emergency care when it is needed?	46.51	38.70
5 Should you participate the rehabilitation process after discharge?	47.67	47.31
6 Is it essential to obtain special procedures with the positive approach of health staff?	59.30	48.38
7 Should you to discuss about palliative care before obtaining treatments?	34.88	35.48
8 Should you ask questions for further clarification?	39.53	38.70
9 Should you receive medical reports, insurances reports with the correct mentioning of treatment procedure?	27.90	29.03
10. Is it essential to specify the name of special person /institute as secondary health opinions by primary health care provider?	34.88	31.18
11 Should you know the name and designation of health care provider prior to obtain treatments?	61.62	65.5
12. Is it essential to receive privacy in hospital set up?	87.20	88.17
13 Is it essential to obtain informed consent prior to treatment procedure?	67.44	75.26
14 Should you think that you can refuse treatment procedures?	38.37	44.08
15 Should you discuss secondary treatment if the primary treatment is not improving?	65.11	46.23
16. Is it essential to receive continually of care?	60.46	68.81
17 Can you complain about treatments if you are not satisfied with them?	46.51	65.59

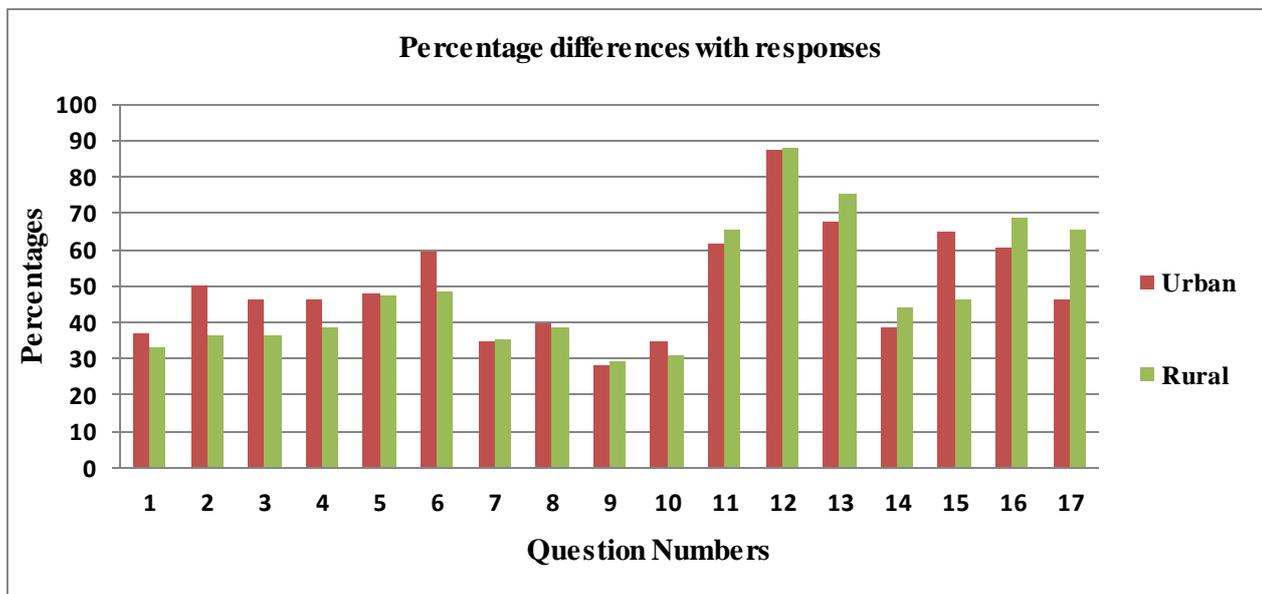


Figure 2: Percentage differences with responses for urban and rural participants

Rural and Urban participants were equally aware about the patients’ rights charter .Participants with urban residence admire safety of environment more than residences of rural and they participate the process of decision making process ,and receiving the care in emergency when it is needed. Even numbers of participants value the rehabilitation process after the treatment regimen (47%).More participants with the urban areas had positive approach on special procedures in specific situations than rural participants. Percentage differences were equal in obtaining the treatments of palliative care (34%) and clarifications on treatment process (38%).Less percentages of rural and urban

participants responded with medical insurances and obtaining the medical reports (27%).More urban participants depend on primary health care staff on obtaining the name of the secondary care personnel while more rural participants concern about the name of health care provider.87% of urban participants and 88% of rural participant satisfy about the privacy that they obtained and most of them were not aware about informed consent or refusal of treatments. Most of participants of urban look for secondary treatments while primary treatment failed while rural participants are seeking for the continuity of care and not satisfied with the care they receive.

Table 4: Responses with level of education

RESPONSES WITH EDUCATION LEVELS

Table 04 and the figure 03, 04 summarizes the percentage differences relation to education level



Q.NO: International Conference on Health and Medicine	Grade5 (Yes %)	O/L (Yes %)	A/L (Yes %)	Degree (Yes %)
1 Do you know about charter of patients rights?	4.76	24	45.61	69.23
2 Should you consider environmental safety and healthy while receiving treatment procedure?	19.04	32	49.12	80.76
3 Should you Participation in the process decision-making with health care provider?	23.80	28	52.63	69.23
4 Should you receive emergency care when it is needed?	33.33	34.66	45.61	65.38
5 Should you participate the rehabilitation process after discharge?	33.33	33.33	54.38	84.61
6 Is it essential to obtain special procedures with the positive approach of health staff?	47.61	38.66	63.15	80.76
7 Should you to discuss about palliative care before obtaining treatments?	33.33	28	40.35	46.15
8 Should you ask questions for further clarification?	23.80	30.66	45.61	61.53
9 Should you receive medical reports, insurances reports with the correct mentioning of treatment procedure?	0	22.66	40.35	42.30
10. Is it essential to specify the name of special person /institute as secondary health opinions by primary health care provider?	14.28	32	40.35	34.61
11 Should you know the name and designation of health care provider prior to obtain treatments?	57.14	66.66	61.40	65.38
12. Is it essential to receive privacy in hospital set up?	71.42	93.33	87.71	84.61
13 Is it essential to obtain informed consent prior to treatment procedure?	66.66	66.66	80.70	69.23
14 Should you think that you can refuse treatment procedures?	28.57	44	40.35	46.15
15 Should you discuss secondary treatment if the primary treatment is not improving?	61.90	52	56.14	57.69
16. Is it essential to receive continually of care?	61.90	68	57.89	73.07
17 Can you complain about treatments if you are not satisfied with them?	47.61	68	56.14	61.53

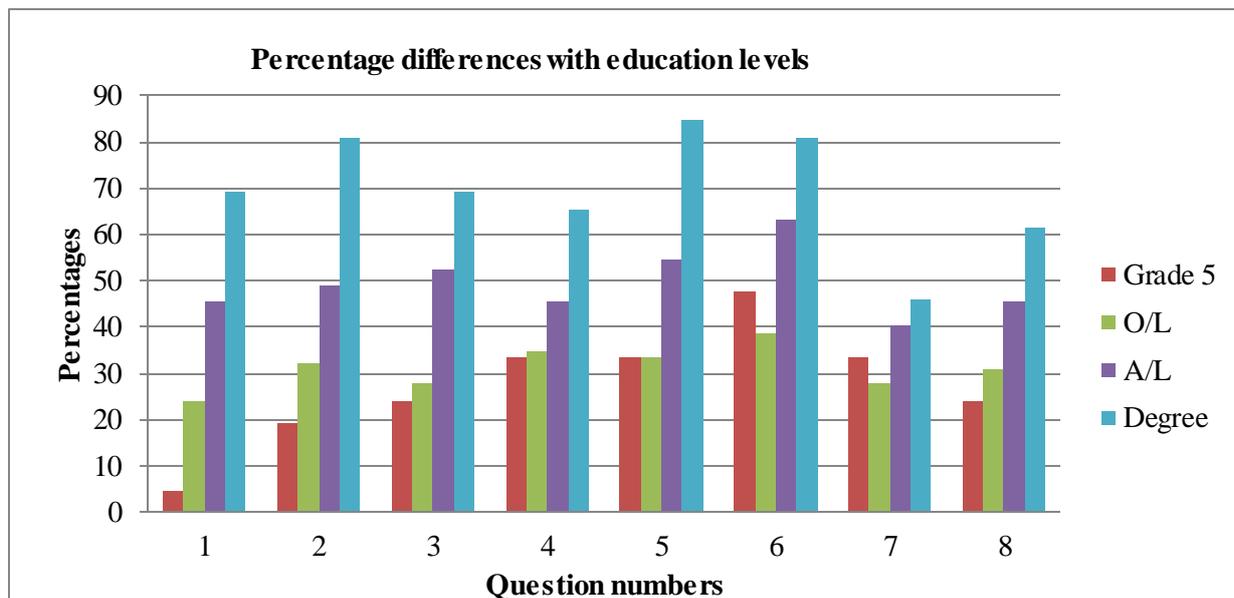


Figure 3: Percentage differences with responses for educational level (Q1-Q8)

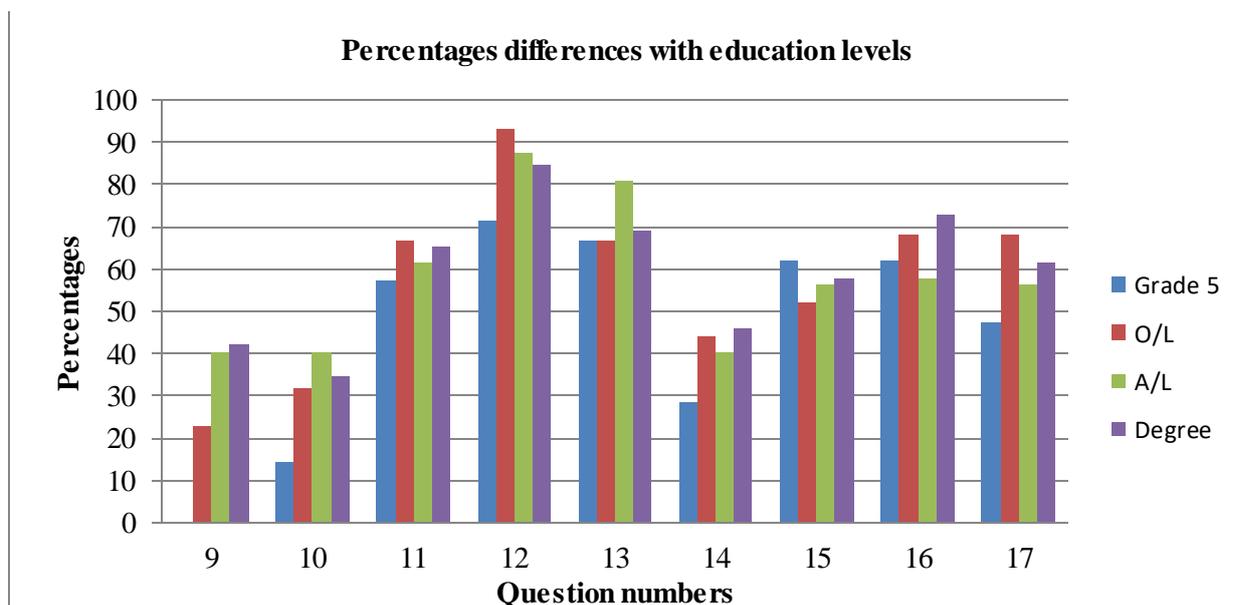


Figure 4: Percentage differences with responses for educational level (Q9-Q17)

Knowledge on charter of patients’ rights varied with the level of education.4% of participants with the education up to grade 5 had heard about the charter while 69% of graduates heard about the charter.80% of participants up to the degree level of education admire environmental safety and privacy while receiving the

treatments .Participating with the process of decision making increases with the levels of education. Even numbers of participants had an idea about receiving emergency care.Even numbers of participants educated up to grade 5 and ordinary levels need and identify rehabilitation after discharge process and



special treatment procedures. Participants in every education levels hadn't clear idea about palliative care. (Grade 5- 33.33%, O/L-28%, A/L-40.35%, Degree -46.15%). Discussions with the health care personals variate with the level of education, people with tertiary level education discussed more about their health plans. Participants with the education level up to grade 5 hadn't idea about the medical insurances and medical records and they were not aware about the process of health insurances (0%), and they mostly depend on health staff in the process of secondary opinions. Every participants were satisfied about the level of privacy that they are receiving (Grade 5- 71.42%, O/L-93.33%, A/L-87.71%, Degree -86.64%). Percentage responses increase with the level of education in obtaining informed consent, refusal of treatments, continuity of treatment regimen, and secondary health care. Participants with the degree level education were more prone to complain about health care when it is not applicable (61.53%), while participants with education up to grade 5 were less prone to complain (47.61%).

DISCUSSION

Charter of patients' rights amendment through the Universal Declaration of Human Rights (UDHR) 1948 with the aim of recognizing "the inherent dignity" and the "equal and unalienable rights of all members of the human family. As Sri Lankans our rights are covered under the UDHR, because we have not implemented specific charter to protect patients' rights. In the rapidly evolving field of medicine decision making process and obtaining value for their rights is essential. Objectives of the research were to identify awareness, attitudes and the knowledge of the patients' rights and to identify how it varies with the area of residence and level of education. Awareness between gender and age

groups could not implement due to time constrain. Considering of the analyzed results Sri Lankans were not familiar with the name of the charter of patients' rights and the process of receiving optimum health care. Hassanemamirazavi 2006 assess the awareness of the charter of patients' rights in Teheran and identify most of patients' in emergency department were not aware about the charter of patients' rights (60%). And it is said that it is a responsibility of health care provider to protect and concern about rights of hospital admitted patients' and patients' awareness of their rights leads to minimize the authority of health systems. Brazinov 2004 reporting about attitudes towards the quality of health care and patients' rights depend on identifying the responsibilities of the health care providers and patients.

It is a right to talk privately with health care providers and have health care information protected, read, copy your own medical record and ask that health care provider to change your record if it's not correct, relevant, or incomplete. According to research results Sri Lankans were satisfied with the privacy that they obtained. Patients' privacy consists with environmental, cultural, informational and proper medical equipments. It is said robust and sustainable patient safety program requires the adoption of best practices, active participation in continuing education and training, reward and recognition programs, and a willingness to conduct regular evaluation and measurement activities. (National Association of Public Hospitals and Health Systems 2004). Vlayen 2011 discussed about the cultural safety in hospital set ups and identified that communication is the main barrier to optimize the patients' rights. Access for the accurate and easily-understood information about your health plan, health care professionals, and health care facilities approved as patients' rights. And patients', who speak another



language, have a physical or mental disability, understand something clearly, are protected to gain informed health care decisions. According to Green 2000 survey was followed to carry out to identify the levels of communications, and interaction among health care providers and patients, and results suggested that ability of decision making were high with the women positive interactions, “Breast Cancer Risk and Genetic Testing is an interactive, multimedia computer-based decision aid to educate individuals and help facilitate informed decision-making about genetic testing for breast cancer susceptibility”. American Academy of Family Physicians Foundation recommends disclosed that “patients and physicians engage in a process of shared decision-making (SDM) to decide whether to get a PSA test. To engage in SDM, the patient must understand the risks and benefits of the test. However, the amount of time available for physician-patient discussion during appointments is limited, and there is empirical evidence that a physician's unstructured verbal remarks regarding the risks and benefits of the PSA test may be misunderstood by patients. Alternative methods to inform patients about the risks and benefits of prostate cancer screening are needed.”As it is proved level of education play key role in the decision making procedure. Ability of communications and shared decision making depends on level of social knowledge.

When primary health opinions have failed it is a right to choose health care providers as secondary opinions who can give you high-quality health care, but the selection mustn't be depend on forceful ideas of primary health care providers, and it is allowed to discuss and to go for further decisions. Smith 2011 indicated that “communication problems between patients and health care workers are far too often at the root cause of inadequate medical treatment, unnecessary errors, excess pain, minimize the

quality of health care and even death. There are lots of reasons for these communication problems. Many actions has to be done to overcome above problems as *understanding* Language and culture issues between patients and providers , *Overcoming* language and cultural communication barriers, *Understanding* communication barriers between providers and communication vulnerable patients not related to language or culture”. American medical association (2010) discloses the informed consent as, the patient's diagnosis, the nature and purpose of a proposed treatment or procedure; the risks and benefits of a proposed treatment or procedure; alternatives; the risks and benefits of the alternative treatment or procedure; and the risks and benefits of not receiving or undergoing a treatment or procedure. It is a process of communication with health care provider and more than simply signing out the document .It is called as shared decision making, which improves the quality of health care and legalized pathway to optimize the safe environment for the protection of the health care providers as well as patients. Brezis et al (2008) described Quality of informed consent for invasive procedures to assess quality of informed consent among patients undergoing procedures and patient's preferences about decision-making. And he describes Most patients do not remember receiving explanations about risks or alternatives for procedures, and physicians resist attempts to improve informed consent. Tools should be developed to measure the quality of consent. Since patients significantly differ in their preferred mode of decision-making, the informed consent should be patient-specific.

As patients are able to make sound decisions, they have the right to refuse any test or treatment, even if it means you might have a



bad health outcome as a result and can also legally stand when the decisions are not applicable. Finding of the research reveal that even participants with higher level of educations are not too keen on involving in decision making. This is consistent with “Sri Lankan patients generally have a great respect for medical professionals and place a lot of confidence in them. They believe doctors do their best to preserve their lives and to improve it” (Silva 2008). Palliative care defines as Medical or comfort care that reduces the severity of a disease or slows its progress rather than providing a cure. For incurable diseases, in cases where the cure is not recommended due to other health concerns, and when the patient does not wish to pursue a cure, palliative care becomes the focus of treatment. Results consistent with Joseph 2009 as saying the majority of participants felt that palliative care can be best given at homes rather than hospitals. The aim should, therefore, be to train a good number of doctors, nurses, community workers, and volunteers in palliative care based on our requirements. Training should also target communication skills and proper manner of breaking bad news to patients and their family members as well. Research results do not consistent and applicable with the comparing with Valorie 2009. Rural areas face a number of challenges in doing this, and thus dedicated attention must be given to determining how to best enhance service delivery in ways that are sensitive to their particular needs. The purposes of this article are to determine the vision for establishing secondary palliative care service hubs (SPCH) in rural communities through undertaking a case study, and to ascertain the criteria that need to be considered when sitting such hubs.

It is a right to a fair, fast, and objective review of any complaint against the health plan, hospitals or other health care personnel. This includes complaints about waiting times,

operating hours, the actions of health care personnel, and the adequacy of health care facilities. According to discussions most of the participants were unhappy with the long waiting hours in general hospitals, They are not familiar with the names and designations of the health care personnel's. National Healthcare Quality (America) 2006 report assembled by the [Agency for Healthcare Research and Quality \(AHRQ\)](#) had presented these sobering assessments on protection of patients' privacy and stressed the value of protecting privacy. Health insurance is a must; it saves money and covers unexpected calamities. Health insurance comes in handy to meet emergencies of severe ailment or accident. Sometimes it is associated with covering disability and custodial needs. Based on research resulted both rural and urban participants were not aware with the medical insurances.

Finding of the research suggest awareness about the patients' rights varied with the level of education. The most important factors associated with the perceived quality of informed consent were the patient's level of education and types of surgery (Brezis 2008). This was more apparent among participants with graduate level education. Medical ethics dictate that the patient has the right to know about the disease, treatment options and prognosis. The knowledge of the above must be impacted by the most suitable member of the healthcare delivery team. In Sri Lanka specific charter for patients' rights is not amendment but they are covered by UDHR (Universal Declaration of Human Rights). But people do not identify rights as the patients, and it is clear large gap of knowledge between participants with A/L and Graduate qualifications. The findings of the study similar to findings of the study done in Karachchi (Bhurgri 2004) reporting “This is an indicator that our formal education curriculum lacks the teaching of individual rights and ethics, thus this could be



categorized as a simple case of ignorance of patients' rights” Participants were not familiar with the specific document which discussed about the patients’ rights. Research results indicate that they are not familiar with UDHR, or Charters of patients’ rights.

LIMITATIONS

There are some limitations to this study. Firstly, this study was conducted among community set up in kandy district only. Hence the results are not reflective of the prevalent clinical practice in Sri Lanka.. Secondly, there is potential for information bias towards giving whatever the respondents thought would be acceptable responses to the researcher, rather than revealing the whole truth. ”. Third was the language barrier as translation had to provided due to questionnaires were not prepared in “Tamil” medium.Assumptions had to be made that given information were true and correct. Participants were educated about the purpose of the study prior to data collection to avoid ethical issues. As future research work suggestions can be made to select equal numbers of participants for variables, limit prolong research periods. All these factors can be used to minimize the issues and limitations in sampling. Research can be implemented in actual ward setup, Questionnaires can be distributed in three native languages (Sinhala, Tamil, and English), to minimize informational bias.

SUGGESTIONS

Well-informed medical professionals could help patients to use patient's rights, and the inherent responsibilities and possibilities, in a proactive manner. Many countries seek to develop and expand partnerships between health care professionals (physicians, nursing staff, pharmacists and others) and the people who use the services provided. Patient's rights

legislation is a good step forward in that process. It also helps to stock up information brochures and pamphlets that can be carried home with the patient.*Hassan Emami Razavi* 2006 said that an official order is needed to install the patient rights charter in all crowded places of hospitals, that motivated evaluate the patient rights both from the patients' and resident points of view. So it is needed to make familiar with the charter of patients’ rights.

Methods of social marketing, consensus development, professional and continuing education and media based enhancement of public awareness of patients' rights should be implemented to enhance the knowledge. *Brazinov* 2004 suggested that continuous upgrading of education of health care employees in medical bioethics, and strengthening the active role of patients in pursuing their rights would be of a significant benefit. *Vlayen* 2011 discussed the value of communications, implementing team work, management actions in protecting the safety of patients.Studies have shown that simplification and repetition of consent information and multi-media presentation have improved subject understanding. (*Eyler*2006). Communication between members of the research team and subjects and their families throughout the course of the research study is a key to successful research participation. It is important to keep in mind that informed consent is an ongoing process that should continue throughout the course of the study and the research purposes.

CONCLUSIONS

Health as a fundamental human right was recognized in the World Health Organization's Constitution stating that the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, and



political belief, economic or social condition. Although patient's rights as individual rights are universal, the mechanism of their implementation and their real contents vary between countries. Patient's rights largely confine themselves to regulating the relationship between the patient and the health care provider or institution and do not seem to have much normative meaning in the relationship between the patient and public authority.

This research reflects the awareness, knowledge and attitudes towards patients' rights and how it varies with level of education, residence area from a selected sample. The findings highlight certain key areas of deficiencies in knowledge such as "identify documents which are stated on patient right", "obtaining medical records and medical insurances", and ask about "secondary health opinions". According to results awareness do not vary with area of residences while it varies with education level, Awareness about the patients 'rights and ability of communication increases when the level of education increases. The findings of this research provide an opportunity for health care providers and community to improve the quality of health care. Systemic approach in education and training at the national level is needed to improve medical ethics. Knowledge on "Patient rights" should be included in to school level curricula and should be published among communities. Native languages should be utilized in the process of communication. Since different patients have different backgrounds the informed consent should be prepared in a manner that would be specific to a particular patient. As future work, suggestions can be made to select participants to cover areas of whole country, , and implement surveys in an actual ward setup so it would yield information that would reflect better the level of awareness and knowledge regarding patients' rights of the

Sri Lankan community. Final goal can be optimized throughout the patients' satisfaction with the aim of quality of care.

REFERENCES

- Brezis, M, Israel, S, Weinstein, Birenshtock, A, Pogoda, P, Sharon, A. and Tauber, R.(2008).Quality of informed consent for invasive procedures. *Israel international journal for quality in healthcare* 20(5): 352-357.
- Crooks, V.A, Castleden, H, Schuurman, N and Hanlon, N (2009) Visioning for secondary palliative care service hubs in rural communities: a qualitative case study from British Columbia's interior *BMC Palliative Care* 8:15
- Emamirazavi , S.H, Azadikalili , M., Saiidi, A. and Shidfar, F. (2006). An evaluation of adherence to the patients' rights charter among patients and physicians at emergency department of imam hospital Teheran. *Daru suppl* 1
- Eyler, L.T and Jeste, D. V. (2006) Enhancing the Informed Consent Process: A Conceptual Overview. *Behav Sci Law.* 24:553-568.
- Green, M. J. (2000).Commentary: Computers and genetic counseling: Time for a dialogue. *Journal of Genetic Counseling.* 9 (4): 359-361
- Hughes, R.G, Patient Safety and Quality: An Evidence-Based Handbook for Nurses. Ronda, G, Hughes, M A. and Blegen. "Chapter 37 Medication Administration Safety"
- Joseph, N, Jayarama, S and Kotian, S (2009) A comparative study to assess the awareness



- of palliative care between urban and rural areas of Ernakulum district, Kerala, Indian Kuzu, N.A, Ergin, A.A. and Zencir, M.A. (2006) Patients' awareness of their rights in a developing country. *Public Health* 120(4): 290-296
- Manjavidze, I, Beriashvili, R and Zarnadze, I. (2009). Assessment of physicians' awareness of patient's rights in Georgia. *Georgian Med News*. 168:89-91.
- Mark, V., Williams, M.D., David. Baker, M.D., Ruth, M., Parker, M.D and Joanne, R. (1998) Relationship of Functional Health Literacy to Patients' Knowledge of Their Chronic Diseases -A Study of Patients With Hypertension and Diabetes *Arch Intern Med.*;158:166-172
- Nkrumah, G.A., Manu, A., Atinga, R.A. (2010). Assessing the implementation of Ghana's Patient Charter Health Education, 110 (3):169 – 185
- Ojwang, B.O., Ogutu, A.E. and Matu, M.P.(2010). Nurses' impoliteness as an impediment to patients' rights in selected Kenyan hospitals *Home* 12: 2
- Patients' rights charter (1996) "Constitution of the Republic of South Africa (Act No. 108)" Available Online: <http://www.ncf.org.za/docs/patientrights.html> (Down loaded: Nov 2, 2011)
- Patients rights (2011) "world health organization .Available online: <http://www.who.int/genomics/public/patientrights/en/> Genomic resource center (Down loaded: Nov 4, 2011)
- Patients' Rights (2011)"patients' rights" Available online: <http://www.patientsrightscoalition.org/About-Us/Fact-Sheet.aspx> (Down loaded: Dec 4, 2011)
- Silva, S.K.L.A., Silva, P.M.K.R., Lakshan, M.T.D. and Patheipan, A. (2008). Awareness among cancer patients about their disease, management and prognosis. *Ceylon Medical Journal* 53: 51
- Smith, H and Pietrzyk, A (2011) Annotated Bibliography on Patient-Provider Communication. American Academy of Family Physicians Foundation
- Wagner, N and Ronendoi, I. (1996) Ethical Dilemmas Experienced By Hospital and Community Nurses: an Israeli Survey. *Nurse Ethics* 3 (4):294-303
- Zülfikar, F and Ulusoy, F.M. (2001) Are Patients Aware of Their Rights? A Turkish study. *Nurses Ethics*. 8:6 487-498

ANNEXURE-(A)-CONSENT FORM

AWARENESS AND KNOWLEDGE ABOUT THE PATIENTS' RIGHTS AMONG RESIDENTS OF KANDY DISTRICT

Research project (HRD 05) as a partial fulfill of the Diploma Course in Human Rights.

Center for Human Rights

University of Peradeniya



Peradeniya

Consent Form prior to fill the questionnaire

The information provided will be treated as highly confidential and will be used only for the research purpose. Your participation is highly valued.

Thank you.

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ANNEXURE (B)

**AWARENESS AND KNOWLEDGE PATIENTS' RIGHTS AMONG RESIDENTS OF
KANDY DISTRICT**

Center for Human Rights

University of Peradeniya

Serial no:

Questionnaire



The information provided will be treated as highly confidential and will be used only for the research purpose. Your participation is highly valued.

Please mark (✓ in front of the correct answer

Age	:						
Ethnicity	:	Sinhala	<input type="checkbox"/>	Tamil	<input type="checkbox"/>	Muslim	<input type="checkbox"/>
Gender	:	Male	<input type="checkbox"/>	Female	<input type="checkbox"/>		
Monthly income	:		<input type="checkbox"/>		<input type="checkbox"/>		
Occupation	:						
Education Level-(up to)	:	O/L	<input type="checkbox"/>	A/L	<input type="checkbox"/>	Graduate	<input type="checkbox"/>

1. In an illness, where do you go to get treatment?

Government hospital	<input type="checkbox"/>
Private hospital	<input type="checkbox"/>
Family doctor	<input type="checkbox"/>

18. Mention the specific document which covers the patients' rights of Sri Lankans

.....

THANK YOU



	Yes	No
1 Do you know about charter of patients rights?	<input type="checkbox"/>	<input type="checkbox"/>
2 Should you consider environmental safety and healthy while receiving treatment procedure?	<input type="checkbox"/>	<input type="checkbox"/>
3 Should you Participation in the process decision-making with health care provider?	<input type="checkbox"/>	<input type="checkbox"/>
4 Should you receive emergency care when it is needed?	<input type="checkbox"/>	<input type="checkbox"/>
5 Should you participate the rehabilitation process after discharge?	<input type="checkbox"/>	<input type="checkbox"/>
6 Is it essential to obtain special procedures with the positive approach of health staff?	<input type="checkbox"/>	<input type="checkbox"/>
7 Should you to discuss about palliative care before obtaining treatments?	<input type="checkbox"/>	<input type="checkbox"/>
8 Should you ask questions for further clarification?	<input type="checkbox"/>	<input type="checkbox"/>
9 Should you receive medical reports, insurances reports with the correct mentioning of treatment procedure?	<input type="checkbox"/>	<input type="checkbox"/>
10. Is it essential to specify the name of special person /institute as secondary health opinions by primary health care provider?	<input type="checkbox"/>	<input type="checkbox"/>
11 Should you know the name and designation of health care provider prior to obtain treatments?	<input type="checkbox"/>	<input type="checkbox"/>
12. Is it essential to receive privacy in hospital set up?	<input type="checkbox"/>	<input type="checkbox"/>
13 Is it essential to obtain informed consent prior to treatment procedure?	<input type="checkbox"/>	<input type="checkbox"/>
14 Should you think that you can refuse treatment procedures?	<input type="checkbox"/>	<input type="checkbox"/>



15 Should you discuss secondary treatment if the primary treatment is not improving?

16. Is it essential to receive continually of care?

17 Can you complain about treatments if you are not satisfied with them?