

PATIENTS' READINESS TO PARTICIPATE IN HEALTH RESEARCH AT NAIVASHA COUNTY REFERRAL HOSPITAL, NAKURU COUNTY, KENYA

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ABSTRACT

Patient readiness into participation in health research is a worldwide concern. Patient's participation in health research is key in advancement of public health and medical research. It is increasingly recognized as a key component in the redesign of health care processes and advocated as a means to improve patient safety. Achieving genuine patient participation is difficult. This study purposed to determine the patients' readiness to participate in health research at Naivasha County Referral Hospital, Nakuru County, Kenya. The study adopted a cross-sectional study design. Utilized convenience sampling technique from patients seeking medical care. The study adopted interview method of data collection which was analyzed with assistance of SPSS version 22. The study result indicate: (63.1%) age would not influence their participation, 57.3% were aware of their rights, 63% were aware of health research. On participation willingness level; 34.1% (personal interviews), 23.1 % (filling out questionnaire), at 24.1 % (donating sample) and 18.7 % (Clinical trials). Also indicated 66% their condition wouldn't affect willingness to participate. And 82% reported if they had chronic illness would be willing to participate in health research. The study established that: majority of the patients aware about health research, though information was inadequate. The study concluded that age, culture, religion and marital status influence patients' willingness to participate in health research. Most patients were willing and ready to participate in health research if requested to do so at another time. Personal interviews were the most favorable level of participation by patients.

Keywords: *Patient, Health research, readiness, participation*

1.1: Introduction

Patients are the primary source of information in health research. Patient participation can include a broad spectrum of activities for human subjects during clinical trials, however, their readiness to participate in health research is a concern. Patient's readiness to participate in health research is key to advancement in public health and Health research. Their participation updates, evaluates procedures and interventions in prevention, diagnosis, screening, treatment, and quality of life.

Patient participation is increasingly recognized as a key component in the redesign of health care processes and is advocated as a means to improve patient safety (Longtin et al, 2010). The development of a patient-centered approach to medicine is gradually allowing more patients to be involved in their own medical decisions. However, this change is not happening at the same rate in clinical research, where research generally continues to be carried out on patients, but not with patients (Sacristán, et al, 2016). Achieving genuine patient participation is difficult. Despite the many benefits of clinical trials, little research has been done to investigate readiness or willingness of patients to participate in such research.

Patients' motivations for participation included potential personal benefit and altruistic reasons. A high proportion of patients were found willing to donate tissue and repeat biopsies for research. Of which majority felt they should be informed of results and more detailed information (Moorcraft, et al. 2016).

Patient's motivation to participate in Health research has been associated with many reasons not limited to: hope of therapeutic benefit, *potential* personal *benefit* and altruistic *reasons*, benefit others particularly relatives (Nurgat, et al, 2005, Moorcraft, et al. 2016, Hallowell, et al 2010). Participation involves both patients and non-professional caregivers such as family members and any significant others who support the patient.

The study recognizes that health research involves the participation of diverse populations. To improve patient participation in health research and clinical trials, a good understanding of patients' readiness and willingness to participate is important.

Much on patient readiness to participate in health research is not documented; therefore the study aims to explore into patients' awareness levels, personal factors and willingness levels into participation in health research at Naivasha County Referral Hospital, Nakuru County, Kenya. Thus, this study will be the first of its kind to examine explore awareness, the personal factors and readiness of patients to participate in health research.

1.4: Objectives

The study was guided by the following objectives and questions.

1.4.1 Broad objectives

To determine the readiness of patients to participate in health research and their awareness, at Naivasha County Referral Hospital, Nakuru County, Kenya

1.4.2 Specific Objectives

- (i) To determine the awareness of patients on health research at Naivasha County Referral Hospital in Nakuru County, Kenya
- (ii) To determine the personal factors associated with patient's readiness to participate in health research at Naivasha County Referral Hospital in Nakuru County, Kenya
- (iii) To determine patient's readiness levels to participate in health research at Naivasha County Referral Hospital in Nakuru County, Kenya

1.5 Limitations

The study faced some challenges not limited to Patients' health status during the interviews and Language barrier. Though, was able to involve only patients who were in stable condition to participate. Translation into local dialect were done to patients' who had a challenge in understanding Kiswahili and English well.

RESULTS

2.1 Background information of the Participants

The study interviewed 103 respondents of whom 52% (females) and 48% (males). On educational level; 37% (tertiary), 30% (secondary) and 33% (primary). On religion affiliation: 95% (Christians), 3% (Muslim) and 2% (other religions). Marital status: 53% (Married), 39% (single) and 8% (divorced). Occupations; 43% (self-employed), 28% (employed) and 30% (unemployed). Age group; 15% (below 20), 26% (21 -25), 19% (26-30), 13% (31-35), 9% (36-40), 5% (41-45), 7% (46-50), and 7% (51 thru Highest age).

2.2 Awareness Levels

The study sought to determine the awareness level of patients on health research at Naivasha County Referral Hospital in Nakuru County, Kenya. Study analyzed various variables whose result are presented as below.

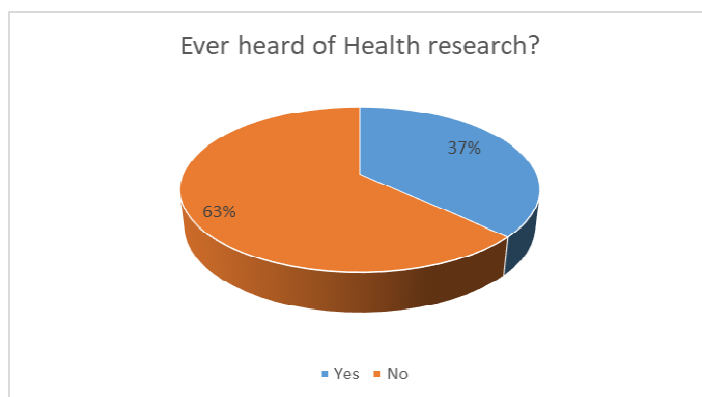


Figure 1: If ever heard of Health research

Result on figure 1 indicate that among respondents 63% had never heard and 37% had heard of health research.

Table 1: If heard of Health research per gender

		Yes	No	total
Sex	Male	36.0%(18)	64.0%(32)	100.0%(50)
	Female	37.7%(20)	62.3%(33)	100.0%(53)
Total		36.9%(38)	63.1%(65)	100.0%(103)

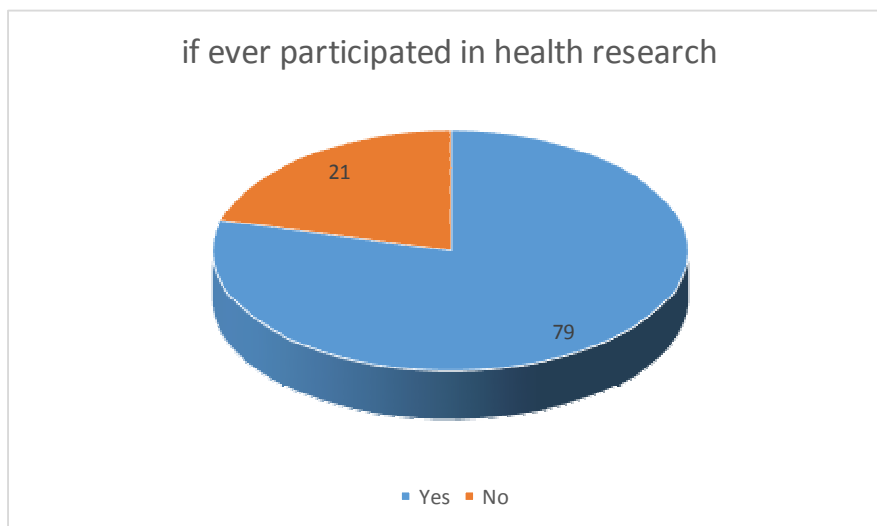
Result in table 1 above indicate that among respondents 64% of male had never heard and 36% had heard, while female 62.3% had never heard and 37.7% had heard of health research.

Table 2 If Yes, What Have you heard About It?

	% (n)
Research on diseases	50(19)
Research on drugs	42.1(16)
Theoretical research	7.9(3)
Total	38

Table 2 indicates on what category of research those who had heard of research knew, 50% (19) heard about research on diseases such as cancer, HIV and hypertension. 42.1% (16) on drugs which included drug trials such as antiretroviral drugs and diabetic drugs and last 2.9% (3) about theoretical research

being done by interviewing and filling questionnaires.

*Figure 2: If ever participation in health research*

Result in figure 2 shows that among those who heard of health research 79% (30) participated in health research while the other 8(21%) had never participated in health research despite having heard of it.

Table 3 If yes, source of health research information

	%(n)
Other participants	16.7(5)
Media for example TV, Radio or Print	46.7(14)
Health care professionals	33.3(10)
Personal participation	3.3(1)

Results in table 3 above show that among those who heard of health research, 46.7 %(14) media sources, 33.3 %(10) Healthcare professionals, 16.7% (5) and 3.3% (1) prior personal experience.

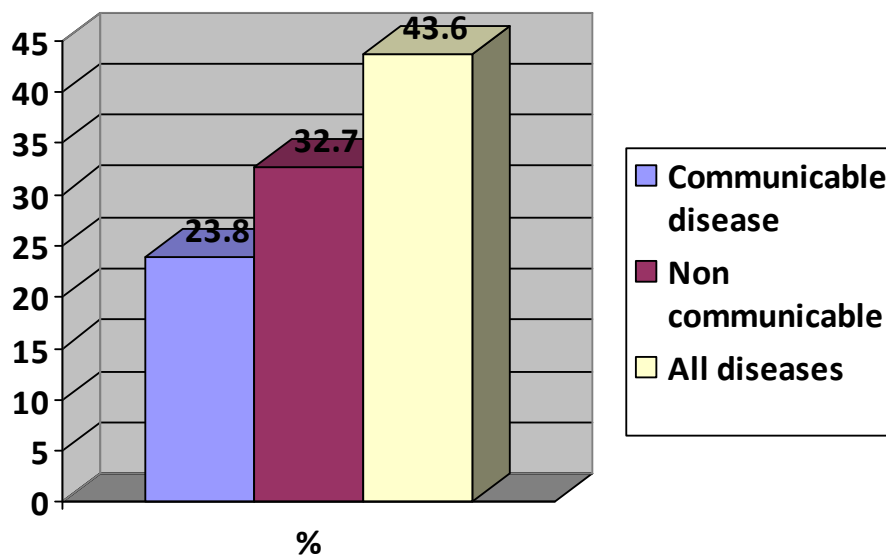


Figure 3: What kind of patients do you think should participate in Health Research?

Results in figure 3 regarding the kind of patients that should participate in Health Research, majority 43.6% were of the opinion that patients with all kinds diseases should participate, 32.7% patients with non-communicable diseases like Cancer, Hypertension and Diabetes and 23.8% patients with communicable diseases such as malaria, TB and HIV should participate in health research.

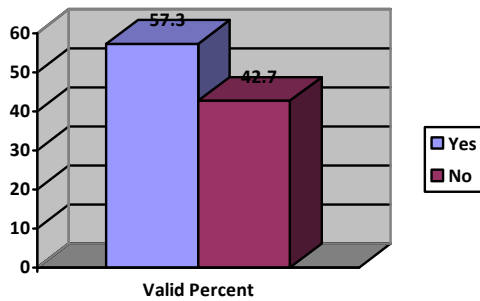


Figure 4: Rights of patients participating in research

From the study, results in figure 4 show that 57.3% of participants were aware of their rights while 42.7% did not have an idea of what their rights as patients to participate. Some of the rights cited were such as right to refuse to participate and right to ask for results of the research.

2.3 Personal Factors

The study sought to determine the personal factors associated with patient's readiness to participate in health research at Naivasha County Referral Hospital in Nakuru County, Kenya

The study analyzed respondents view on personal status as influencing factors in readiness to participate in health research. The results were as follows:

Among the patients interviewed, 27.2% reported that their occupation would influence readiness to participate in health research while, 72.8% indicated their occupation would not affect their participation. While 14.6% indicated their marital status influence their willingness to participate in health research as they needed consent from spouses while 85.4% would participate in health research regardless of their marital status.

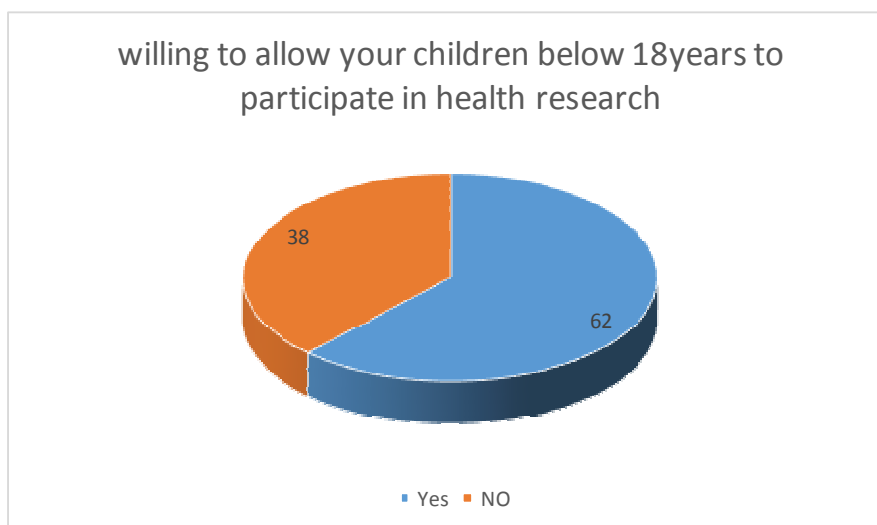


Figure 5: would you allow your children below 18 years to participate in health research?

Results in Figure 5 indicates that 62% report they would grant consent, while 38% wouldn't.

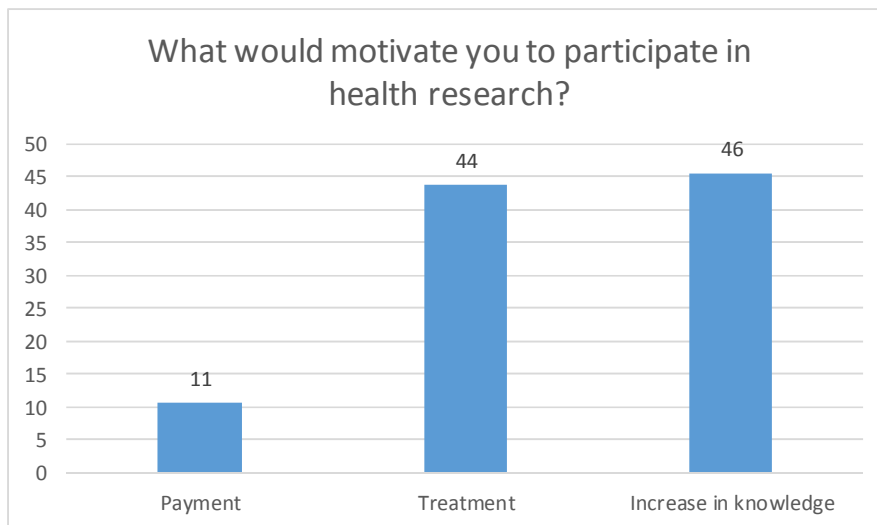


Figure 5: What would motivate you to participate in health research?

Results on figure 5 shows that most respondents would be motivated mostly by an increase in knowledge at 46%, treatment at 44% with payment factor at 11%.

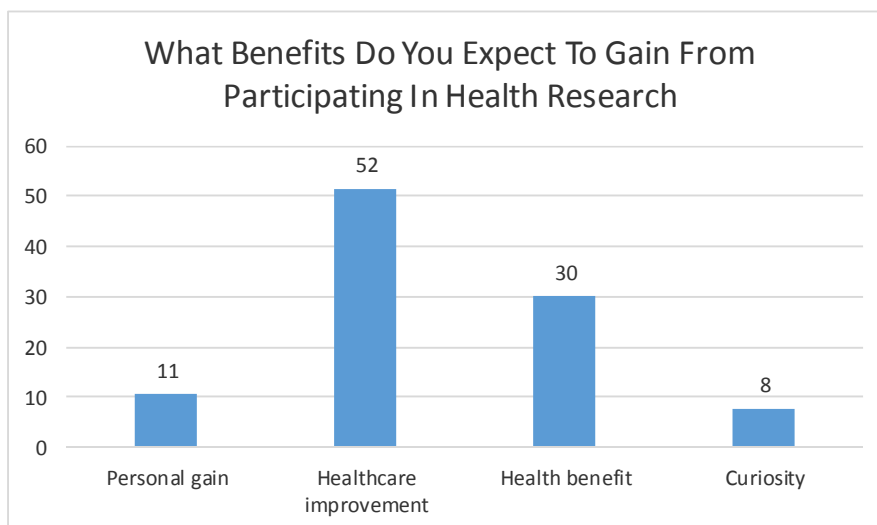


Figure 6: What Benefits respondents expect to Gain from Participating in Health Research

Results on figure 6 indicate that participants' benefits as: 52% expected health care improvement, 30 % health benefit , 11% personal gain and 8% curiosity satisfaction..

2.4 Willingness levels

The study sought to determine the personal factors associated with patient's readiness to participate in health research at Naivasha County Referral Hospital in Nakuru County, Kenya

The study results revealed that out of 103 respondents 87% had never participated in health research while 13% patients had participated in a health research programme before.

With regards to educational level, results indicated that 18.4% had tertiary level, 16% had secondary level and 3% primary level.

Among those who had a prior experience with participation in health research, 47 % (6) were involved in personal interview, 39 % (5) had blood withdrawn, 15 % (2) filled out questionnaires and none had participated in clinical trials before.

Also among patients who had participated before, 92% (11) were willing to participate in health research again if call upon.

Of which they would participate in personal interviews at 34 % (31), filling out questionnaires at 23 % (21), donating samples at 24 % (22) and Clinical trials at 19 % (17) if call upon.

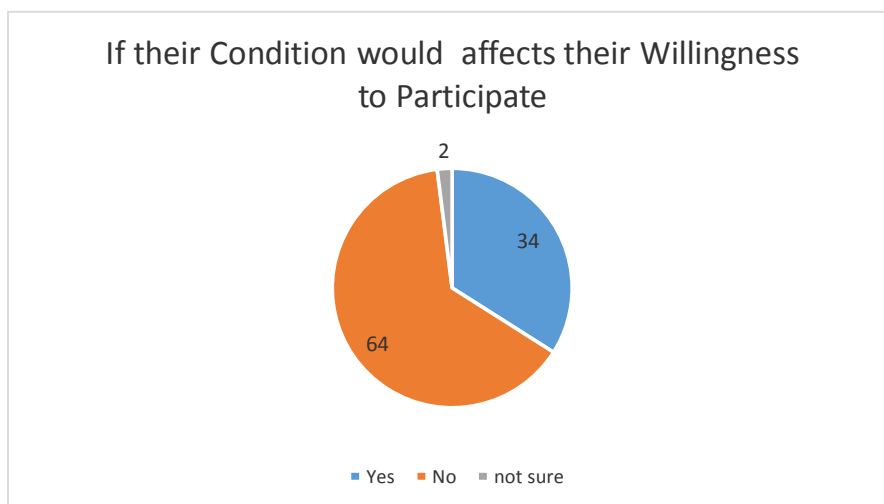


Figure 7: If their present health condition would affect their participation on health research

According to result in figure 7, 64% felt their health condition wouldn't affect willingness to participate, while 34% would hinder their participation, while 2% were not sure of it.

DISCUSSION

3.1 PATIENTS AWARENESS TOWARDS HEALTH RESEARCH

The study sought to determine the awareness of patients on healthcare research at the Naivasha County Referral Hospital. Little research has been done before on general awareness of patients on healthcare research.

The study results revealed that 63.1% of respondents were not aware of health research activities involving the patients. Farther, revealed that healthcare research sources to patients were: media and internet sources (46.7%), healthcare professionals (33.3%) and other participants (16.7%). Similarly, Chu *et al* (2015) study revealed that 86% had a general idea on patient participation on health research from the mass media, among other sources like Television, radio, newspapers, internet and advertisements in hospitals..

Sahay *et al* (2005) indicated that factors associated with increased willingness to participate in these trials were awareness of current efforts, importance for self, concern about adverse events among others.

Du *et al* (2018) reported that most patients who are willing to participate lack adequate information on health research. He also suggested that if patients received more information through their treating physicians, health researcher enrollment and positive attitude towards participation might improve, 91% preferred to be informed about research findings.

Study findings revealed on awareness on types health researchers conducted: on diseases such as cancer, HIV and hypertension (50%), drug trials (42.1%), while theoretical research (2.9%) by interviews and questionnaires. Little is done on the same

Of which also those aware had heard of: sample donation (37.9%) tissue and organ donation. had in clinical trials/drug trials (31.1%), filling questionnaires (17.2%) and personal interviews (13.8%).

Patient viewed that patients with both communicable and non-communicable diseases (42.7%), non-communicable diseases such as diabetes, hypertension and cancer (32%) while communicable diseases such as malaria and tuberculosis (23.3%). According to Sacristan *et al* (2016) 75% of patients with diabetes would prefer clinical trials, similarly to Moorcraft *et al* (2016) study showed patients treated with palliative intent (oncology cases, diabetes and hypertension) were more willing to participate in clinical trial.

The study results showed that 57.3% of the respondents were aware of their rights as participants in a research programme. Some of the rights mentioned were: right to consent and feedback information on the results of the research. Du *et al* (2018) study supports the same, 91% of patients preferred to be informed about research findings or else would not participate in future clinical trials. Though contrary to Mastaneh *et al* (2013) study on the same that indicated total awareness of patients to their rights was minimal.

3.2: PERSONAL FACTORS THAT INFLUENCE PATIENT'S WILLINGNESS TO PARTICIPATE IN HEALTH RESEARCH

3.2.1 Age

The study results revealed that 63.1% of the respondents thought that age would not influence their participation in health research, particularly all age groups. This is contrary to Davis *et al* (2007) study which revealed that age was a factor that influenced patient participation in health research where younger patient played a more active role in health research than older patient. This also correlates with the study according to Trauth *et al* (2000) which demonstrated that the determinants of willingness included being middle aged.

3.2.2 Gender

Study results showed that more females (20) were aware of health research compared to males (18) out of the total 38 participants who were aware. This is similar to Davis *et al* (2007) study which revealed that females participated in more active role than males. Johnson *et al* (1994) indicates that women's exclusion from clinical research became an issue of public scrutiny and political debate, as they were women's underrepresented in drug trials.

3.2.3 Culture and religion

The study results reveal that 89.3% of participants had no religious restrictions, while 10.7% of participants were for the idea that their religion would affect their participation levels. While 63.6% indicated that their cultural beliefs would hinder their participation while 36.4% had n cultural restrict to participation. The findings agree with Belcher *et al* (2006) study that found where culture and religion play a passive role in patients decision to participate.

3.2.4: Marital status

The study reveals 14.6% of the respondents their marital status would influence their willingness to participate in health research while 85.4% didn't influence. The findings are contrary to Chu *et al* (2015) study which had found no association between marital status and participation in clinical research.

3.2.5: Benefits

Castillo, (2012) Over two-thirds (64.4%) of participants reported "knowledge, awareness, and/or information about colonoscopy and general health" as being the greatest benefit they received.

3.2.6: Motivating factors

The study findings reveal that most patients would be motivated by an increase in their level of knowledge (45.6%) as compared to financial compensation (10.7%) and treatment (43.7%). This results contrast the Walsh, & Sheridan,(2016) study on study that identified participation in clinical trials was motivated by participant gaining access to treatment (33%) and 36% belief that participation enabled others to be helped.

3.2.7: Concerns

With regards to what was the patients' concerns on health research participation it reveals that 49.5% was due to deterioration of health status, 22.3% about their privacy, 17.5% over death and 9.7%. A study by Weingart *et al* (2011) stated that the experience of a serious adverse event could decrease a patient capacity to participate in clinical trials. Walsh, & Sheridan,(2016) also reported similar findings on her study that the perceived threat of danger or harm resulting from participation in a clinical trial was among the major concerns in participants. Other participants also raised concerns about invasive procedures that could potentially cause deterioration of their health. The results were similar to Walsh, & Sheridan, (2016) study that found that cost was among the leading factors influencing participant readiness to participate. Costs, according to the study, included financial, medical and time costs.

3.4 WILLINGNESS LEVELS

Kasner et al (2009) study indicated that demographic factors, clinical factors, and prior knowledge about research have little impact on the decision to participate in acute stroke clinical trials.

The study results revealed that 88.9% of the respondents were willing to participate in health research. Of which 12% having previously participated in a health research. This is similar to a study done in Tunisia by Boudia *et al* (2016) where 80% of their respondents were willing to participate.

Among the respondents 91% of those who had participated again were willing to participate again in another research which is similar to Anderson *et al* (2018) study that found 93.4% were open to participating again. An interesting revelation from the study results was that 63.1% of the respondents had never heard of health research yet were willing to participate and this is consistent with Sheblaq *et al* (2019) whose study findings indicated 75.33% were willing to participate again. However, Glass *et al* (2015) study found that with more specific information creating more awareness, more people were willing and that those with previous participation experience were equally more willing to participate in other research.

From the study results, on willing to participate or participate again 34.1% desired a personal interviews, 24.7% sample donation and blood withdrawals, 23.1% filling questionnaires while 18.7% with clinical trial which is in contrast to Moorcraft *et al* (2015) study that found majority of patients were willing at 78% and 75% to donate tissue samples and consent to biopsies respectively.

The study results in relation if their health condition would affect their willingness that 64.1% wouldn't be affected while 34% cited they will be affected due to reasons like disability thus that it would hamper their participation.

Lastly, the study results revealed that 77.7% of those who wished to participate were willing to participate if they had a chronic disease such as hypertension, HIV and diabetes compared to 8.7% and 7.8% if they had a sub-acute or acute disease. This was similar to Brom *et al* (2014) study that found chronically ill patients were more willing to participate in health research especially those in later stages of terminal illness. In contrast, by Boudia *et al* (2016) a survey done in Tunisia found that only 38% were willing to participate despite had life threatening conditions.

CONCLUSION AND RECOMMENDATIONS

3.1 CONCLUSION

The study established the readiness levels of patients at Naivasha County referral hospital to participate in health research including their awareness levels, various personal factors that affected their readiness and the willingness levels to participate. Below were the major findings.

3.1.2 Awareness levels

The study established that majority of the patients were not aware about health research and patients' participation as there is lack of adequate information about health research. Common sources of knowledge on health research was through media. Research on diseases such as cancer, HIV and hypertension was most common types of research known, and viewed that research should involve all kind of patients.

3.1.3 Personal factors

The study revealed that personal factors such as age, culture, religion and marital status play a minimal role in influencing patients' willingness to participate in health research. Healthcare improvement was the major motivating factor for most respondents to participate in health research and a bid to increase wealth of knowledge in health. Major concern affecting patients' participation was health risks associated with participating in health research.

3.1.4 Willingness levels

Despite the lack of awareness about health research most patients were willing and ready to participate in health research if requested to. The study established that personal interviews were the most favorable level of participation by patients. Furthermore, participants were more willing to participate in health research if they suffered from chronic illnesses.

3.2 RECOMMENDATIONS

From the findings, the study recommends to research institutions and hospitals on the following:

1. Farther research to be undertaken on patients' participation in health research in relation to factors associated.

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