

# Ethical Issues at the Interface of Physiotherapy Care and Research Practice in Pediatric Oncology-Descriptive Study

Malarvizhi D<sup>1</sup>, Metha K S<sup>2</sup>

<sup>1</sup>Dean, <sup>2</sup>BPT IV YEAR, SRM College of Physiotherapy, SRM Institute of Science and Technology, Kattankulathur, Chennai, TamilNadu, India

## Abstract

Pediatric oncology has a major role in research. This paper discuss about the ethical consequences of physiotherapy care and research in Pediatric Oncology. Empirical ethics is a broad division, grasping, difference in indicating ethics and empirical research. A major Australian tertiary teaching hospital reveals that 65 % of patient presents with specific indication for physiotherapy, in that only 12.8% are receiving physiotherapy. Indications includes in physiotherapy care are pain, lymph- oedema, incontinence, respiratory and musculoskeletal Problems also it includes hard to move. Physiotherapy has extensive role in palliative oncology, it also has large preventative ,educative and supportive roles to play and provides independent and complementary therapies for physical debility and pain. Pain from reflex spasm and contracture are dealt with Physiotherapists. Founded that no reference based on standard of life and quality-adjusted life years in terms of preventing dependence and avoid hospitalisation. Treatment of pediatric oncology often has physically, socially and psychologically demands. Always there must be some ethical reason for all the decision on treatment and care for a patient with cancer. It is a fact that ethics needs not only all the stakeholders to do the right things but also it needs the one who do it in the right way. Research practice has led us to great advances in pediatric oncology and the proportion is greater in children than adults. Obtaining the informed consent and assent was the most important ethical challenges faced during the research.

**Key words:** Ethical issues, Pediatric oncology, Empirical research, Physiotherapy care, consent ,assent

## Introduction

In Pediatric oncology, children were treated for cancer to increase survival rate. Pediatric with oncology overall survival rate has improved to 25% - 75 % in last 5-years compare to past 30 years due to improvement in supportive care.<sup>1</sup>Pediatric oncology has a major role in research ideas.As a consequences, many Physiotherapist are indulged in both physiotherapy care and research. The national and international protocols, explained the information of treatment procedure for each type of cancer. In research 70% of children present with cancer are enrolled in study they were from developed country and enrolls even during their cancer treatment.<sup>1</sup>The process of research and Physiotherapy in the Pediatric oncology has more ethical challenges. Aim of this paper to differentiate between the Physiotherapy care and research practice on children with cancer.<sup>1</sup> A major Australian teaching hospital reveals that 65 % of children presents with particular indication in physiotherapy, in

that only 12.8% are getting physiotherapy.<sup>2</sup> Indications includes in physiotherapy care are pain, lymph-oedema, incontinence, respiratory and musculoskeletal problems also it includes hard to move.<sup>2</sup>

Today ,the involvement of physiotherapy on Pediatric oncology has specific roles which are evidence based :Prevention -target specific exercise and education programs, Acute and post acute – bio psychosocial to pain management, Institutional and community based rehabilitation - Easy measure (eg. wheel chair training after spinal cord compression, gait training for neurological dysfunction and Palliative care -Physiotherapy specific skills such as TENS used for relief pain , lymph-oedema and incontinence programs , laser therapy for wounds and ulcer management and maintenance of free movements and physical function.<sup>2</sup>

The health-care professionals described many ethical issues facing on physiotherapy and research on

pediatric oncology based systematic literature.<sup>3</sup>

## Methodology

A study design was descriptive study .Empirical evidence was more popular and most important from a applied ethics ,especially in bioethics. It also has broad category ,grasping different explanation about the content in ethics and empirical research.<sup>7</sup>To gain empirical information, we collected a article based on descriptive study on observation of parents ,children and physiotherapist in physiotherapy care and research practice .The experiences about the ethical issue on pediatric oncology research has the goals. The goals are such as research , informed consent ,interests and therapeutic misconception. The knowledge of children , parents and physiotherapists in research gives deep understanding in research and the ethical role in research practice.<sup>8-9</sup> There are different type of empirical research and ethical reflection :firstly - empirical ethics states that the study of people' belief , intuitions , behaviour and information is meaningful in ethics and it has the emerge ethical points ; secondly - empirical ethics accept that the methodology (with descriptive methods such as collecting article related experiments ,interviews and observation) ; thirdly - empirical ethics states that the contrast across descriptive and prescriptive study.<sup>10</sup>

## Discussion

Analysis of 10 studies were reviewed, it has the contrast between research and physiotherapy care in pediatric oncology .It has problem with informed consent and learn about research setting. Its has the consequence of disappear boundary between research and physiotherapy care . Also ethical view has different in treatment and research goals.<sup>1</sup>

Martine C de Vries et al 2011 described in term of research , the researchers find the information about what would be the best treatment for children with oncology and improve the interest in research in academic merit. Pediatric oncology child therefore undergo the procedure like blood sample , spinal taps and PET scans not related to treatment goals. Ethics has different two-dimensional treatment and research were provide by the various types of ethical principles. Normally parents and physiotherapist will discuss the idea on what the child interest and make it to use concept on consent.<sup>1</sup>

And the treatment should given on the interest of the individual child . Respect given for rights incorporates two ethical decision : 1)The individuals were willing to participate in study 2)the person with smaller or less rights entitled to protection.<sup>1</sup>Respect to rights of the individuals they were voluntarily to participate in the research with basic information about the research and the consent.<sup>1</sup>The research and physiotherapy care has the different in methods simultaneously applied to everyday practice of pediatric oncology .It have the consequence for the informed consent and the child with interest are difficulty to identify by the parents and physiotherapists.<sup>1</sup>Pediatric oncology has many difficulty to get an good informed consent process , specially regarding diagnosis and treatment . Informed consent of participation has there own decision making after understanding the treatment protocols and research and make the participant to participate in the both research and physiotherapy care.<sup>1</sup>The consent form has the following : explaining concept and method it has difficult to understand about it .Although the parent has difficulty in understanding about the informed consent in research such as the risk factors ,the procedure , the alternate treatment , the duration of study, the right to dropout and the voluntaries to participate.<sup>1</sup>The duty of parents to care the child , the parents are enrolling their children in clinical care and some will take interest to make their child to participate in research. Motivate and support the research to prevent the future generation from the occurrence . The misunderstanding were happen in between research and clinical care of physiotherapy , parents were mix up the research and clinical (treatment protocol) its has the major disadvantage. The study has revealed that 40 - 80 % of subjects has misunderstanding of the research.<sup>1</sup> Not only parents are confusion but also the physiotherapist has confusion while conducting,both research and clinical session simultaneously.<sup>1</sup>

Liisa Laakso et al 2006 stated thatpalliative care provide both positively team based and community based activity. Approaching the advice and care of a therapist has the effectively utilizes and experience the health care and benefit.<sup>2</sup>

Jean-Claude K Dupontet al 2016 concluded thatthe wide spread of ethical issues founded in pediatric oncology . It shows the therapists , parents and child take interest to participate in the research.<sup>3</sup>The

evidence of positive and negative effect of participants were offering research in pediatric oncology.<sup>3</sup> Ethical reflection were need to develop in pediatric oncology community among a person with an interest and have the knowledge about it.<sup>3</sup> Empirical ethics has the difficulty to find out the result with individuals studies . Difficulty to document the informed consent because of the misleading communication or misunderstanding about the research.<sup>3</sup> It has the categories such as (misconception , misestimating or misunderstanding )

Cecilia Bartholdson et al 2014 described based on this study finding it has divided into two domains , which has the objectives of study : ethical related and dealing with ethical related concept.<sup>4</sup> Ethical related issues has dealing with truth about the children diagnosis , treatment and prognosis are unknown to children and the parents prevents the truth- telling to the children. Preventing Truth - telling has the ethical issues and stress to the parents.<sup>4</sup> parents and therapists has protect and preserve the truth - telling still the end of the life . The many results of the study has shown the goals achieved by the child were interest to participate in the study .On major , the pediatric with cancer will affect the family , relatives and caregiver .Because the pediatric is present with cancer.<sup>4</sup>The current study has pain relief as the major goals.

lynette Rashleigh et al 1996 stated that the physical dangers occurs in end stage of cancer and that are managed by the trained professional to deal with it , as a part of physiotherapy.<sup>5</sup> In physiotherapy ,the main aim is to reduced the pain in cancer patient .To avoid unnecessary and expensive drug intake by cancer people and involve the people in community level physiotherapy by the patients and care givers.<sup>5</sup>

Stacey L et al 2007 concluded that clinical research has been necessary to improve mortality rate and reduce disorder and improve treatment related to the disease in children with cancer .Before that obtaining informed consent and assent from the child participants . It has the major Challenges on pediatric oncology , children and parents to understands about it.<sup>6</sup>

### Conclusion

Research will be continued to improve survival rate and decreasing disease morbidity rate in pediatric

oncology. Above all studies found difficult in obtaining informed consent and assent from both parents and children to participate .Researcher and therapist found difficulty to make the parents and children understanding about the procedure and the protocol.Major ethical issues founded were parents were confused with treatment protocol in both research and clinical care practice.

**Ethical Clearance:** Departmental Ethical clearance was obtained .

**Conflict of Interest:** Nil

**Source of Funding:** Self

### References

- 1) Martine C de Vries, Mirjam Houtlosser et.al., Ethical issues at the interface of clinical care and research practice in pediatric oncology: a narrative review of parents' and physicians' experiences, *BMC Medical Ethics* 2011,12:18.
- 2) Liisa Laakso,GradCertHlthMgm et.al.,The role of physiotherapy in palliative care, 2006,35:10.
- 3) Jean-Claude K Dupont, Kathy Pritchard-Jones et.al.,Ethical issues of clinical trials in paediatric oncology from 2003 to 2013: a systematic review,Elsevier,2016,17(5),187-197.
- 4) Cecilia Bartholdson,Klas Blomgren,et.al., Experiences of Ethical Issues When Caring for Children With Cancer, *cancer nursing* ,2015,38(2),125-132.
- 5) lynette Rashleigh, Physiotherapy in palliative oncology,Australian journal of physiotherapy, 1996,42(4),307-312.
- 6) Stacey L.Berg,Ethical Challenges in Cancer Research in Children.The oncologist 2007,12:1336 -1343.
- 7) Borry P, Schotsman, P et.al., Editorial: Empirical ethics: A challenge to bioethics. *Medicine, Health Care and Philosophy* 2004,7(1):1-3.
- 8) De Vries MC, Van Leeuwen et.al., Reflective equilibrium and empirical data. Third person moral experiences in empirical medical ethics. *Bioethics* 2010, 24(9):490-498.
- 9) DenzinNK, LincolnY et.al., Handbook of qualitative research Thousand Oaks:Sage Publications, 2000.
- 10) Borry P, Dierickx K et.al., The Birth of the Empirical Turn in Bioethics,*Bioethics* 2005, 19(1):49-71.