UNIVERSITI TEKNOLOGI MARA

DEVELOPING CLINICAL ETHICS SUPPORT FOR PAEDIATRIC PRACTICE AT HOSPITAL AL-SULTAN ABDULLAH

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ABSTRACT

The field of clinical ethics has played a crucial role in addressing the ethical issues and dilemmas that healthcare professionals face in their clinical practice. Clinical ethics support services have evolved into the institutional ethics support provided within health systems in various countries around the world, with three primary functions-(1) case consultation, (2) education, and (3) policy review or development. Unlike adult medicine, paediatric practice presents unique ethical challenges that are not frequently observed in adult patient care. While ethical issues in paediatrics are relatively common, the number of paediatric ethics consultations was found to be significantly low in general. That can imply that clinical ethics support services have not been utilised to their full potential in paediatric practice. The need for clinical ethics support for paediatric practice has become more apparent with the advancement of modern medicine due to the numerous ethical quandaries related to paediatric care that have arisen as a result of this. This dissertation explores the development of paediatric clinical ethics support services in various countries and how they have been utilised. In the case of Hospital Al-Sultan Abdullah (HASA), key informant interviews (KIIs) revealed that the paediatricians faced a number of ethical issues related to clinical decision making, surrogate decision making, refusal of treatment by parents, end-of-life issues, and resource allocation issues. The recommendations in this dissertation took into account the ethical issues identified as well as the opinions of the paediatricians. The recommendation focuses primarily on promoting clinical ethics consultation services and the clinical ethics committee at HASA. Enhancing case consultations through grand rounds, providing ethics education and training, as well as guidelines and policy development in paediatric practice, have been highlighted. It is hoped that this dissertation will contribute to the literature on clinical ethics in Malaysia and will also significantly impact the development of a clinical ethics support service in paediatric practice in the country.

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TABLE OF CONTENTS

	Page
CONFIRMATION BY PANEL OF EXAMINERS	i
AUTHOR'S DECLARATION	ii
ABSTRACT	iii
ACKNOWLEDGEMENT	iv
TABLE OF CONTENTS	v
LIST OF TABLES	viii
LIST OF FIGURES	ix
LIST OF ABBREVIATIONS	X
CHAPTER ONE: INTRODUCTION	1
1.1 Background of Study	
1.1.1 Clinical Ethics	1
1.1.2 Paediatric Clinical Ethics	3
1.1.3 Clinical Ethics Consultation Services and Clinical Ethics	4
Committee in HASA	
1.2 Problem Statement	6
1.3 Literature Review	6
1.4 Research Questions	10
1.5 Research Objectives	10
1.6 Research Methodology	11
1.7 Scope and Limitation of the Study	12
1.8 Significance of the Study	12
CHAPTER TWO: CLINICAL ETHICS SUPPORT COMMONLY U'	ГILISED
IN SELECTED PAEDIATRIC HOSPITALS IN T	THE USA,
UK, AUSTRALIA, AND SINGAPORE	13
2.1 Overview	13
2.2 United States	13
2.3. United Kingdom	16

CHAPTER ONE INTRODUCTION

1.1 Background of Study

1.1.1 Clinical Ethics

The clinical practice raises a vast range of ethical issues that healthcare professionals may find difficult to resolve. Healthcare professionals frequently use the term 'dilemma' to explain an ethically challenging situation in which there may be an obvious ethical solution, but achieving that ethical solution may be difficult due to various barriers (Miljeteig et al., 2019). The field of clinical ethics has played an important role in addressing these ethical issues and dilemmas faced by healthcare professionals. Jonsen et al. (2022) stated that clinical ethics is a branch of the larger field of bioethics that uses an organised approach to ethical decision-making in clinical medicine. Callahan (2004) described clinical ethics as the day-to-day ethical decision-making related to patient care that focuses on individual patients. Accordingly, clinical ethics support (CES) has been defined as "the provision of support and advice to health professionals and patients on ethical issues arising from clinical practice or patient care" (Slowther et al., 2004, p.950). Meanwhile, clinical ethics support services (CESS) refer to the types of institutional ethics support provided within different health systems (Schildmann et al., 2019).

In general, the three primary functions of CES have been described as (1) case consultation, (2) education and (3) policy review or development (American Society for Bioethics and Humanities (ASBH), 2009; Slowther et al., 2012). The various modalities that have been used to provide CES include individual case consultation, individual ethicist, ethics rounds, discussion forum, clinical ethics committee (CEC) and moral case deliberation (Slowther et al., 2004; Hurst et al., 2007; Rasoal et al., 2017). The CEC model is one of the most commonly used models in providing CES (Slowther et al., 2004). While the involvement of the CEC in each of the three CES functions differs, there are cases of innovative work in all functions nonetheless. For example, there are committees that involve patients in policy development, utilise role-playing to help