Key Concepts and Issues in Nursing Ethics

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ISBN 978-3-319-49249-0 ISBN 978-3-319-49250-6 (eBook)
DOI 10.1007/978-3-319-49250-6

Library of Congress Control Number: 2017933450

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Printed on acid-free paper

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The registered company is Springer International Publishing AG
The registered company address is: Gewerbestrasse 11, 6330 Cham, Switzerland

To John, Shane and Rebecca.

Foreword

Since its establishment in the late 1960s, modern bioethics has been dominated by a focus on respect for rational and autonomous persons as the pivotal actors in medicine and healthcare. This focus reflects the influence of the Kantian philosophy of autonomous human beings, able to identify and prescribe universal ethical standards to themselves, entirely rational and free from any heterogeneous reinforcement. It also mirrors Mill's appreciation of the high value of human freedom of individuals, only to be restricted when it confines the freedom of others.

The prioritisation of respect for autonomy in modern bioethics has radically changed the perspective in which patients are regarded within healthcare. For millennia, patients were seen as fundamentally incapacitated by pain, suffering, ignorance and disease, thus justifying a paternalistic approach in medicine. In contemporary healthcare – at least in most Western countries – patients are now seen as being fundamentally on an equal footing with physicians. As a positive consequence of the stellar status of autonomy in contemporary bioethics, medical paternalism has lost its justification as the default approach of physicians. On the flipside however, because of its narrow emphasis on autonomy, bioethics has not been giving the phenomenon of human vulnerability its fair share of recognition for quite some time. This is especially problematic, if we accept the claim that "[…] vulnerability is the general predicament of humans, while autonomy is the exception" (Ten Have 2016, 2).

Without attempting anything near to a substantiation of the above claim, it could easily be argued that *Homo sapiens* is one of the most vulnerable species around. *Homo sapiens*, for example, is the only species that after birth needs years and years of continuous care and attention from its parents to be able to survive. At the end of life, many humans are again heavily dependent on others for long stretches of time because of chronic illnesses, neurodegenerative diseases and fragility. So at first glance, vulnerability seems to be an essential human trait, anthropologically on a par with autonomy.

This observation notwithstanding, in bioethics the notion of vulnerability has stood in the shadow of the concept of autonomy for a long period of time. The idea of vulnerability made its bioethical entrée in the Belmont Report in 1978. Here it was applied in the context of research with human participants. The document warned of the danger that "vulnerable subjects" might be disproportionally targeted for research purposes as a “special instance of injustice” (Belmont Report 1978, 19).

After this landmark publication the role of the concept of vulnerability in bioethics continued to be confined to the research context, until it was solidly advanced as an all-round European ethical principle some 20 years later in the BIOMED II project “Basic Ethical Principles in European Bioethics and Biolaw” (1995–1998) (see Rendtorff and Kemp 2000). Not only did this European project elevate the idea of vulnerability to the status of an independent ethical principle, equal to the principle of respect for autonomy, it also broadened its application beyond the realm of research.

In 2005, the bioethical status of vulnerability was further enhanced to that of a universal ethical principle in the UNESCO *Universal Declaration on Bioethics and Human Rights*. Article 8 of this document solemnly states: “In applying and advancing scientific knowledge, medical practice and associated technologies, human vulnerability should be taken into account. Individuals and groups of special vulnerability should be protected and the personal integrity of such individuals respected” (UNESCO 2005) (see Ten Have (2016) for a more elaborate history of the concept of vulnerability in bioethics).

Unlike the average bioethicist – indeed even in contrast to physicians – nurses have always had abundant exposure to the full plethora of patients’ vulnerabilities. That may be the reason why in nursing literature the concept of vulnerability already started to figure in a prominent position in the 1970s. McGilloway, for example, distinguished two traits of the patient’s predicament relevant to nursing: “The first is that the patient’s dependency places him in a vulnerable situation, and second that his situation is such as to make rational judgement difficult for him” (McGilloway 1976, 229).

More recently, Sellman (2011) used the concept of vulnerability as central for the understanding of the aims of nursing. He distinguished between “ordinary and extra-ordinary vulnerability” (Sellman 2011, 51). Whilst human beings in general are susceptible to a variety of harms, some are significantly more susceptible than others. This particular susceptibility might be such that they need care and assistance from others in ways that are normally not necessary for persons with only ordinary vulnerability. Nursing can accordingly be understood “as a response to the additional human vulnerability that comes with being a patient” (Sellman 2011, 51). As extra-ordinary vulnerability involves reduced chances for human flourishing, the true aim of nursing can thus be regarded as “[…] the promotion of flourishing for more-than-ordinarily vulnerable persons” (Sellman 2011, 51).

At the start of this stimulating volume on nursing ethics, the editor, Anne Scott, rightly refers to Sellman’s understanding of nursing in terms of vulnerability. This sets the tone in her introductory chapter exploring the ethical aspects of nursing in general. The following four chapters analyse nursing from the perspective of a selection of established ethical theories: utilitarianism, deontology, virtue ethics and care ethics. The remaining chapters then focus on a variety of crucial topics in nursing ethics.

As indicated above, nurses can tap into a rich and exclusive experiential background. This gives them a privileged position as contributors to bioethics debates. Their perspective on vulnerability is only one case in point. They have never neglected this phenomenon to the extent that it was overlooked in mainstream bioethics. The lucky readers of this thought-provoking volume will encounter many other examples of the ethical significance of the distinctive nursing perspective.

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Preface

The idea for this book has taken some time to come to fruition! When I started to teach health care ethics to nursing and medical students in the mid-1980s, there were very few texts on health care ethics available in Ireland, or the UK, and almost none dedicated to nursing. This has changed remarkably in the intervening years, and there are now many such texts to choose from.

However, the nursing role continues to develop, change and become increasingly complex. In my experience many students find nursing ethics a challenging and somewhat obtuse subject. Those of us engaged in teaching ethics to nursing students can struggle to convince students of the value of the subject matter, and to engage them effectively in discussion and analysis of the ethical dimension of their practice. It seems to be important, to student understanding of the topic, that the approach to teaching nursing ethics is well grounded in a description of nursing that students can recognise, accept and engage with. For this reason, through the use of short case studies, each chapter of this book uses examples of nursing practice that are based on, and informed by, actual experiences of receiving nursing care.

In recent years, we have witnessed the publication of a number of reports of inquiries into patient care. These reports have had some very strong messages for nurses, and health service managers, regarding the quality, value, and impact of nursing care-on both the patients' experiences of care and the outcomes of that care. Some of these reports articulate, in a very powerful way, the deeply intertwined nature of the ethical and the clinical aspects of nursing practice and the provision of nursing care. Many of the chapters of this book make direct reference to the findings and analyses of these reports.

Good nursing, nursing that is explicitly and consciously rooted in a clear understanding of the ethical dimension of nursing practice, is essential to safe, humane patient care; never more so than in situations of significant pressures on the health care resource.

This book provides an opportunity, and an invitation, to examine the ethical dimension of nursing practice; through a variety of theoretical lenses, across a number of patient care situations, and throughout the human life span. It also tries to strike a balance between a recognition and articulation of the ethical responsibilities of the individual nurse to provide humane, sensitive, and competent care to her/his patients, and the responsibility of the organisation within which nurses work to support nursing staff in providing this care.

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Acknowledgements

This book would not have been written without the contributions of many people. It has been a privilege to work with the contributing authors over the past year. Thank you for your thoughtful contributions and willingness to engage in discussion and review. A number of authors and colleagues generously provided comments on my own chapters – in particular, I would like to thank Alan Kearns, Janet Holt, Derek Sellman and Marcia Kirwan. John Scott, as ever, has been there whenever, and for whatever, required. I am deeply grateful for his support and critical friendship. Shane Scott worked with me throughout the summer-reading, editing and commenting on all the contributions to this book. His incisive comments and editing skills have been of significant value in challenging my ideas and in bringing this project to a successful conclusion. Rebecca Scott introduced me to Word formatting tools – but ultimately decided it was easier to use these herself in my service – it has been fun and somewhat amazing to watch.

I also wish to express my thanks to Nathalie Lhorset-Poulain and Rekha Udaiyar of Springer; to Nathalie for encouraging me to initiate this project in the first place and for her rapid responses when I needed to check elements of the process; to Rekha for her advice, follow up and generally keeping us all on track!

Finally, I would like to thank all my students over the years, in Ireland, Scotland, England and Kenya, for their engagement, insights and stimulating discussions.

Contents

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Heike is currently involved in a number of European projects: She is the chair of a COST Action (CHIPME, IS1303) on "Citizen's Health through public-private Initiatives: Public health, Market and Ethical perspectives", she is leader of ethics deliverables and chair of the Ethics Board of a H2020 project (MARIO) on assistive robotics for elderly with dementia, and she was subject expert in research ethics on a capacity building project (UNIVERSITARIA) for Romanian Universities in 2015.

Ann Gallagher Ann is a Professor of Ethics and Care at the University of Surrey and Director of the International Care Ethics (ICE) Observatory. She has extensive experience as a nurse, ethicist, teacher, researcher and editor of the international journal *Nursing Ethics*. Ann has researched areas such as dignity in residential care, compassion in the NHS, professionalism in paramedic practice, ethical aspects of professional regulation and ethics education in social care. She was trained as a general nurse at the Royal Victoria Hospital in Belfast during 'the troubles' and as a psychiatric nurse at West Park Hospital, Epsom, Surrey. Ann is a member of the Nuffield Council on Bioethics and co-Chair of the Princess Alice Ethics Committee. She has co-edited *Ethics and Nursing Practice*, second edition (2016), with Ruth Chadwick.

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Janet Holt Janet Holt is a Senior Lecturer in the School of Healthcare at the University of Leeds. She is a registered nurse and midwife, with a BA (Hons) in Philosophy from the University of Leeds, an MPhil in Applied Philosophy from the University of Manchester and a PhD in Psychology from the University of Leeds. Janet has over 15 years clinical experience as a nurse and midwife both in the UK and in Kenya; as well as experience of working as a research midwife and a research and development practitioner in nursing. Her research interests and publications are within the disciplines of Healthcare Ethics and Nursing Philosophy. A member of the Ethics Committee of the Royal College of Nursing (RCN), she was appointed chair of this committee in 2013. She also represents the RCN on the Ethics Committee of the British Medical Association. Janet chairs the Faculty of Medicine and Health Research Ethics Committee at the University of Leeds and the Bradford Leeds NHS Research Ethics Committee.

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Nursing and the Ethical Dimension of Practice

1

P. Anne Scott

Abstract

Nurses are important to patients. Nurses touch people's lives during some of the peaks and troughs of human existence. Therefore it is important that we think about nurses and nursing. What do our patients require from nurses and how do we, as a society, as nurses, and as health service leaders, meet patient need? The first step is to recognise that nursing, as a practice, has moral values at its core. The nurse-patient relationship, which is central to the provision of nursing care, has ethical importance and is of ethical significance. It is also vital to consider that the context within which nurses practice can shape and be shaped by the moral values of nursing. These moral values form what can be termed the ethical dimension of nursing. It is therefore important that we explore and examine these moral values. Codes of conduct are examples of the nursing profession's collective attempt to express its underlying values. The institutions within which nurses work help or hinder the actual expression of these values in nursing practice and patient care. We need to recognise the interplay of these various factors in order to ensure that we as nurses, as potential patients, and as members of society understand what good nursing practice means, what it looks like in practice, and how it can be supported. This chapter sets out to identify the ethical domain of nursing practice, and signal its relevance for good nursing care and a safe, supportive patient experience. The chapters which follow provide theoretical and conceptual lenses through which to identify, analyse and discuss ethical issues in nursing practice, with a view to providing tools for the nurse to practice in an ethically sensitive and appropriate manner.

Keywords

Ethical domain • Nurse-patient relationship • Nursing ethics • Patient-centred care • Codes of conduct

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P.A. Scott (ed.), *Key Concepts and Issues in Nursing Ethics*,
DOI 10.1007/978-3-319-49250-6_1

Introduction

Nurses are important to patients: to their experience of illness, disease, treatment, and care (Institute of Medicine (IoM) 2011; Scott et al. 2014). Nurses can touch people's lives during some of the peaks and troughs of human existence. Therefore it is important that we think about nurses and nursing. Professional codes of conduct such as those published by the Nursing and Midwifery Council (NMC) (2015), and the Nursing and Midwifery Board of Ireland (NMBI) (2014) are examples of the profession's collective attempt to express the underlying values of the nursing profession. Many of these values are moral values. Recently, in the Irish nursing context, an initiative led by the Chief Nursing Officer, the Department of Health (DoH), and supported by NMBI, sets out to re-identify and recommit nurses to the core underlying values of nursing in Ireland: Compassion, Care, and Commitment (DoH 2016). These values are, clearly, moral values. However nursing practice also happens within a context. This context is the health service of the relevant locality, region, or country. It is necessary to acknowledge, and to fully appreciate, the impact that this context has on the individual practitioner's ability to practice to the best of their ability, including providing ethically sensitive care. Given the nursing literature, education programmes, codes of conduct, initiatives such as that described above (DoH 2016), and recognising the impact of the context of nursing practice, it is important that we explore and examine the morally relevant aspects (in other words the ethical domain) of nursing practice.[1]

Nursing and the Ethical Domain of Practice

The ethical domain of human life relates to how we behave towards each other and the reasons we do so. As the American scholar Martha Levine, writing for practising nurses in the 1970s, succinctly and powerfully states:

> Ethical behaviour is not the display of one's moral rectitude in times of crisis. It is the day-to-day expression of one's commitment to other persons and the ways in which human beings relate to one another in their daily interactions (Levine 1977, p. 845)

The way we relate to one another, behave towards one another, the attitudes we display to other people – whether strangers, neighbours, patients or clients – are moral actions, behaviours, and attitudes. These behaviours, actions, and attitudes are based on personal, as well as professionally socialised, attitudes, judgements and decisions. This is an important matter to recognise. It implies, for example, that despite a difficult working environment, there is personal responsibility on the individual nurse for the care she/he provides. There may also be corporate responsibility, as in situations such as those reported in Mid Staffordshire (Francis

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[1] The terms moral and ethical, while having roots in the Latin and Greek languages respectively, will be used interchangeably throughout this book.

2010, 2013), for a lack of humane, competent nursing care.[2] The nurse may be very busy and stressed by work load, however how she/he receives the newly admitted patient, or responds to a patient's call for help, is in part a personal ethical decision and behaviour. Being fully and continuously aware of this ethical dimension of nursing care is a topic that deserves some attention. It is a topic which we will explore in both this introductory chapter and in all the chapters that follow.

In nursing we interact with human beings made *more than ordinarily vulnerable* (Sellman 2011, p. 67) by illness, disease, or other life circumstances. These human beings need our professional help and care. Good nursing practice therefore requires us to engage at a human as well as a professional level. Patients assume professional competence, until we prove them wrong (de Raeve 2002, p. 158). They seek kindness and compassion as the basis of developing confidence and trust that they are 'in good hands'. They seek to be cared about as individuals, as well as being cared for, by the nurses they encounter. We, the nurses responsible for the care of these patients, may show kindness and compassion through many ordinary interactions and interventions that acknowledge the individuality and human context of the patient – or we may choose not to do so. These choices are at the heart of the ethical domain of our nursing practice.

The ability to recognise the need of the patient: to relate, respond to, and recognise those who are "*more than ordinarily vulnerable*" (Sellman 2011, p. 67) suggests the ability, in the nurse, to develop a basic connection as human being with another human being. In developing this connection we are setting the foundations for a nurse-patient relationship. This is the vehicle through which we provide engaged, connected, and patient-led care. Nurse-patient interaction and engagement, as manifest through the nurse-patient relationship, is at the heart of the moral domain of nursing practice.

Nurse-Patient Interaction: The Nurse – Patient Relationship (Including Case Study)

The American nurse scholar Janice Morse (1991) argues that the relationship between the patient and the nurse is not only the basis and frame within which nursing care happens: the patient-nurse relationship is a direct outcome of a series of interactions, observations, and engagements between the patient and nurse. The nurse-patient and patient-nurse relationship is a negotiated and evolving reality for the duration of the patient-nurse contact. Morse (1991) in her seminal study of the nurse-patient relationship identified four different types of relationship: the clinical relationship, the therapeutic relationship, the connected relationship and the over-involved relationship. The type of relationship that develops, Morse argues, depends "*on the durations of the contact between the nurse and the patient, the*

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[2] For discussion of nurse-patient interaction from the perspective of virtue ethics please see Chap. 4, p. 43–54 below.

needs of the patient, the commitment of the nurse and the patient's willingness to trust the nurse…" (Morse 1991, p. 455).

The clinical relationship is that which is appropriate when the contact is short, functional, and the needs of the patient very discreet – such as the removal of sutures as an outpatient, or the dressing of a minor wound. The therapeutic relationship, which Morse suggests is the most often encountered, goes somewhat deeper than the clinical relationship – contact between the nurse and patient is still relatively brief, patient need is relatively minor, care is given quickly and effectively. In this type of relationship the patient expects to be treated as a patient and has family and friends to meet other psychosocial support needs. Morse suggests that within the context of this type of relationship some degree of testing of the relationship will occur from the patient's perspective, to see if the patient can "trust" the nurse to look after them properly, until they can care for themselves again. This can involve ringing the call bell for a minor matter to see if the nurse will answer, or observing a nurse to see if they will actually return when they have indicated to the patient that they will get back to them on a specific issue. This is likely to be the most common form of nurse-patient relationship encountered in modern acute care settings. However for very dependent and acutely ill individuals their needs require the nurse to be able to flex between the therapeutic and connected forms of the nurse–patient relationship.

The connected relationship either evolves over time, as patient and nurse get to know each other over an extended care period, or is stimulated by the ability of a nurse to respond to the intensity of the patient's need. Morse suggests that

> in this relationship, the patient believes that the nurse 'has gone the extra mile', respects the nurse's judgement and feels grateful, the nurse believes that her care has made a difference to the patient. (Morse 1991, p. 458)

In the over-involved relationship the nurse treats the patient as a person and friend first and a patient second. The nurse can become territorial over the patient believing she/he is the only one who can care properly for this patient. The nurse may become over-extended, lose a sense of balance and suffer impaired judgement. This kind of scenario can lead to impaired patient care and burnout.

The case-study below will help bring focus to our discussion of the nurse-patient relationship, and provide some insight into its importance in understanding the ethical domain of practice, in addition to its potential significance to a patient's experience. This case-study involves a nursing academic and former colleague who had been diagnosed with breast cancer.[3] My colleague kept a diary as she confronted and experienced biopsy, diagnosis, surgery, and prepared for radiotherapy. Her diary provides important insights into both the nurse-patient relationship, and nursing care, from the perspective of an informed patient.

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[3] This narrative is used in a paper published in *Nursing Philosophy*, (Niven and Scott 2003), to explore the role of the patient's voice in determining the appropriate distribution of the nursing resource. I wish to express my thanks to *Nursing Philosophy* for enabling its reproduction in this chapter.

> Being ‘prepped’ consisted of having my breast, axilla, and back painted. The sensation was pleasant; the last pleasant sensation there would be for a breast that had, in its time, been appreciated by baby and lover alike. There was no avoiding the issue, this was what I was going to lose. The nurse and I didn’t talk. She didn’t fill the moment with idle chit chat or pseudo empathy, which I would have found offensive and would have demanded social responses from me that I would have struggled to make. The nurse treated the task and thus me and my soon to be no more breast, with respect. While sharing none of the horrors of pubic shaving, this preoperative preparation was an activity that called for high calibre nursing skills. I was very grateful for the way it was managed; it preserved my dignity, did not exacerbate an intrinsically distressing situation and gave me a sense of, literally, ‘being in good hands’. (CN)

The nurse described here is observant, respectful of her patient, competent, and “managed” the interaction with CN, and the required nursing intervention, in a calm, professional, and respectful manner. It seems reasonable to suggest that the above scenario portrays the “therapeutic” relationship described by Morse.

> On return from theatre it was trained staff who washed me, made me comfortable, gave me iced water to drink while checking heart rate, blood pressure, oxygen saturation, drain, and wound. The sense of being completely cared for, when I was in that post anaesthesia dependency state was wonderfully comforting and reassuring. For a short while I was completely in their hands and their competence was very obvious. Each task done well reinforced the sense of that competence. So it was as important that the water from the face cloth didn’t run down my front as that the drain wasn’t pulled or the wound exposed, forcing me to look at it rather than letting me choose my moment. These demonstrations of hands-on competence created a climate of confidence in the nurses’ expertise. (CN)

Again, in this diary extract, CN describes examples of therapeutic relationships. The nurses remain nameless, part of the effective, competent, caring team. CN then goes on to describe the patient experience and the missed opportunities when that therapeutic engagement is lacking:

> In contrast the first postoperative shower was the domain of the nursing assistant. Of course this cannot be combined with cardio-vascular monitoring in the way that bed-based care can be. And it is a low level activity, with the focus of concern on not letting the patient stumble, get scalded or the wound get wet. Even though at this level the task was completed competently and kindly, my sense, as a patient and as a nurse, is that this first postoperative shower is a key nursing activity, not one to be ‘given away’ to a nursing assistant. As a nurse I recognize the opportunity for proper monitoring of the wound and drain, and much more crucially of the patient’s psychological state. Is she afraid to look and, if so, how best should this be managed? Does she want to talk about it; get information, reassurance that her thoughts and feelings are normal? How does it feel, is hypo or hypersensitivity present, to what extent; how should it be accommodated while showering and dressing? These assessments can be more completely made in the shower than in the bed; and they can be inferred from the patient’s behaviour without the need for intrusive, insensitive, premature questioning. For the patient, the first post-op shower represents her most vulnerable moment, naked, only one breast, a huge wound, a drain, a newly improved view of one’s flabby bits. Not only is the patient confronting this sight for the first time, she is exposing herself to someone else’s view in, for many, a rehearsal of showing her husband or partner. That degree of vulnerability demands a professional’s response. It is the nurse, not her assistant, who has the biological, psychological and sociological knowledge that enables her to deal with the situation appropriately. (CN)

CN's comments here have ethical as well as clinical relevance. Exposure of the patient to this first post-operative shower has ethical as well as clinical salience and shows a potential lack of ethical sensitivity in the delegation of this task to the care assistant. We then find, in CN's account of her interactions with the Clinical Nurse Specialist in Oncology, an excellent description of Morse's "connected" relationship:

> E's skill and respect for me as a patient were evident in a number of ways, on this occasion and on all succeeding occasions. I told her I was scared, I would have told anyone but she made it easy to say to her and her reaction, which was minimal, didn't make me feel foolish. Her behaviour made it entirely clear that she had understood my terror and was reacting accordingly. E knew I was an academic before she met me, so her conversation during the biopsy, clearly designed to distract me, utilised that knowledge. She told me about her Master's degree and the essay she stayed up all night word processing and which had got lost. The topic was familiar enough to hold my attention and to remind me of situations in which I was a competent 'grown up' person; thus boosting my self-esteem and confidence. I nearly passed out at one point. Her skill in dealing with that was very evident – position, comfort, maintaining the circumstances which allowed the biopsy to continue; afterwards a glass of really cold water; keeping someone with me when she had to go. And everything done in a way which allowed me to maintain my dignity. E's behaviour during the biopsy established the basis for my total trust in her. This was vital when she became the person to communicate the confirmed diagnosis and the options for surgery. (CN)

An essential element here may be to make the invisible visible. CN struggles to articulate the ways in which E had provided such vital care:

> The sense of unlimited time and a depth of knowledge about a huge range of vital things – surgery, recovery, side-effects and how best to manage them, the individual differences, the emotional consequences, the hands-on skills and her availability for anything – to be with you the first time you looked, when you got your prosthesis, for my husband, for my daughter, for me when I want, not according to a schedule. … I have seen E many times now and her skills are always impressive but it's at times of shock and distress – diagnosis, admission, post-operatively – that they are most evident. It's like the matching pieces of a jigsaw – what she provides fits your needs so well that it makes something approaching a whole. (CN)

This is a really powerful narrative about good nursing and a real accolade to a number of nurses, but particularly to E; a nurse who clearly provided excellent nursing care and a vital, enriching supportive relationship at a very bewildering and difficult time in a patient's life. The narrative also demonstrates the intertwined nature of the ethical and clinical domains of nursing practice, as manifest in the provision of nursing care.

As this narrative demonstrates, nurse-patient interactions and the provision of nursing care are formed by, and essentially exist as, attitudes, behaviours, and actions; the latter often being highly skilled. This is integral to the very essence of nursing. How one behaves with a patient, how one responds to the patient's need for care, is as much about the nurse's ethical response, ethical behaviour towards another human being who is vulnerable (Sellman 2011; Edwards 2001) or suffering, as it is about the nurse's clinical response. Indeed many authors, including Nortvedt

(2001), argue that it is not possible to divide the clinical from the ethical in many nursing care activities and interventions.[4] From a position of recognising the ethical as well as the clinical response of the nurse, it is a short step to argue that nursing practice, and consequently nursing care, has an important ethical element or dimension. In other words the ethical is inherent in nursing practice and thus to the provision of nursing care (Scott 2006). So how does this play out in the context of patient care? What does the ethical dimension of nursing care and nursing practice actually look like?

From the perspective of the patient, and their families, they seem to want reasonably consistent things from their nursing and medical carers: kindness, compassion, competence, consideration, information, communication, and care (Scott et al. 2014). This does not seem an extreme or unreasonable demand from well-educated professionals in a health system of the twenty-first century, in a developed and relatively well-resourced society. It is also entirely consistent with the conception of nursing that is articulated clearly in our codes of practice. The core values expressed in the NMC (2015) code are

(a) prioritise people,
(b) practice effectively,
(c) preserve safety and
(d) promote professionalism and trust (https://www.nmc.org.uk/standards/code/).

The NMBI (2014) *Code of Professional Conduct and Ethics* describes the following five principles as the core principles that should underlie nursing care in the Irish healthcare context:

1. Respect for the dignity of the person
2. Professional responsibility and accountability
3. Quality of practice
4. Trust and confidentiality, and
5. Collaboration with others (http://www.nmbi.ie/Standards-Guidance/Code).

A reader of the text of these two codes of practice would discover significant similarities in the values being expressed, the description of good nursing, and the types of behaviours and attitudes required of the professional nurse in her/his interactions with both patients/clients and colleagues. These values are also found in recent Irish and UK documentation regarding expectations of nursing and midwifery staff (DoH 2016; Health Education England 2015).

The codes, and the values initiative led by the Chief Nursing Officer in the Department of Health in Ireland, are examples of the profession's collective attempt to express what good nursing practice looks like. These descriptions of good nursing practice are firmly rooted in moral values and a language that expresses the

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[4] Grahame Smith in Chap. 11 of this book also holds this position.

underlying ethical dimension of nursing practice. The codes provide a clear recognition of the reality that nurses can have a profound impact on their patients/clients. Nursing registration and regulatory bodies demand that this impact is beneficial (good) for the patient. In the context of illness and disease the patient experiences heightened vulnerability. She or he is in need of nursing care and attention. This increased vulnerability of the patient combined with the inherent ability of the nurse to assist, support, and nurture the patient/client or to snub, injure, or neglect the patient/client, throws the ethical dimension of nursing into sharp relief. How should recognition of, and insight into, this ethical reality of practice be supported in our everyday nursing care?

The notion that ethics is about our everyday interactions with other people seems as useful in nursing today as it was when expressed by Levine in 1977 (see p. 2 above). It seems particularly relevant, for example, when one considers the descriptions of nursing, found in our rhetoric, literature, and educational texts. We have an extensive nursing literature that claims the importance, or centrality, of care and caring in nursing practice (Edwards 2001; Scott 2014).[5]

Empirical studies exploring nursing support a conceptualisation of nursing care that includes psychosocial support, and a recognition of the patient/client as a whole person, with psychological, social, and physical care requirements (Scott et al. 2006; Ausserhofer et al. 2014). Care is, however, only one of the ethically relevant concepts used in descriptions of nursing practice. de Raeve (2002) considers the importance of trust and integrity in the provision of appropriate patient care. Nortvedt (2001) and Niven and Scott (2003) speak of the need to be sensitive to the personhood of the patient in order to really come to understand what the patient requires from the nurse.

This description of patient need, and the appropriate nursing response, not only assumes an understanding of the patient as a human being who presents both unique and anticipated responses to their illness and circumstances; it also assumes a description and understanding of nursing that sees the nurse as responsive to and equipped to meet these needs. A description and articulation of nursing as a practice capable of meeting such needs is the beginning of a theory of nursing practice. As the above would indicate, this is a theory of nursing practice that sees the good for patients, and nurses' ability to help provide some of these goods, as central to nursing practice.

The good in health care frequently has psychological, social, spiritual, as well as physical dimensions. Recognising the human being who is a patient/client in need in this manner suggests: (1) that practitioners must be sensitive to more than the physical domain of patient experience; and (2) this broader sensitivity calls on involvement of the practitioner, as person, in a distinct way. The clinician and ethicist Søren Holm expresses this latter point thus:

> When you meet the patient you meet another human being who is vulnerable, who trusts you, and whose life you can influence in a significant way. This creates a specific

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[5] For a discussion of care ethics and nursing practice please see Chap. 5.

> responsibility towards this other human being, which can be difficult to understand for outsiders, but which nevertheless plays a significant role in the deliberation of health care professionals. In their minds it is both related to the power they have, and to the respect they have to show. (Holm 1997, p. 127)

The respect and the power over another, that nurses and other practitioners have, and the trust and confidence which patients can be enabled to feel is mediated, normally, through the specific relationship the practitioner has with the patient. Working out what the nurse-patient/client relationship should be takes thought, reflection, and a recognition that different patient-practitioner interactions may require differing responses depending on the clinical context and patient-care needs, as we can see from CN's narrative above. Nursing care should therefore be patient-led and patient-focused (Scott 2014).

However as indicated in the introduction to this chapter nursing and the nurse-patient relationship takes place in a context. This context is that of the particular health care institution, in the local, regional and national arena of health service provision. At a micro level the nurse practices in a ward or community context. The structure of care delivery, the resourcing and the leadership in this context can have a significant influence on the nurse's ability and motivation to provide patient-sensitive, patient-led and patient-focused nursing care. If structures, leadership (institutional and nursing leadership) and resourcing is not supportive of good nursing the efforts of individual nurses will be undermined, nursing morale will gradually deteriorate and nurses will become ill or leave. High staff turnover leads to lack of engagement and commitment and deteriorating patient care. As Canadian scholar Wendy Austin argues:

> … health professionals are increasingly put in peril by healthcare reform that undermines their efficacy and jeopardizes ethical engagement with those in their care. The re-engineering of healthcare to give precedence to corporate and commercial values and strategies of commodification, service rationing, streamlining, and measuring of "efficiency," is literally demoralizing health professionals. Healthcare practice needs to be grounded in a capacity for compassion and empathy, as is evident in standards of practice and codes of ethics, and in the understanding of what it means to be a professional. Such grounding allows for humane response to the availability of unprecedented advances in biotechnological treatments, for genuine dialogue and the raising of difficult, necessary ethical questions, and for the mutual support of health professionals themselves. If healthcare environments are not understood as moral communities but rather as simulated marketplaces, then health professionals' moral agency is diminished … . (Austin 2012, p. 27)

It is the case that the context of nursing practice has changed quite dramatically over the past decade or so in many countries, with the length of patient stay in the acute hospital sector being significantly reduced. This means that the amount of time and opportunities that the nurse has to interact with and get to know the patient is also substantially reduced. Reduced lengths of stay results in increased patient turn over, more acutely ill patients with increased dependency on nursing staff, increased "churn" and reduced down time in which nurses can "recover" and "catch up" with their patients. This has implications for the way we think about nursing and the nurse-patient relationship.

While we, as nurses and as ordinary members of the public, have been upset, even scandalised, by reports of poor care (Francis 2010; Vale of Leven 2014; HIQA 2015), we should also carefully consider potential barriers to providing good nursing care and remove such barriers where there is the possibility to do so. We thus must make the resourcing,[6] context, organisation, and culture of nursing practice visible in order that ethically appropriate practice is not deemed to be the exclusive responsibility of the individual nurse.[7] As Austin (2012) argues:

> The trust that society grants health professionals must be reciprocal. The support and resources necessary for competent, ethical practice have to be available if health professionals are to fulfil their commitments. (p. 30)

Judge Francis, for example, in his reports emphasises how inadequate staffing, lack of leadership, and low staff morale ultimately led to a breakdown of acceptable norms and nursing care (Francis 2010, 2013). Lord MacLean, author of the report from the Vale of Leven Hospital inquiry, draws on both his experience as a patient who contracted Clostridium Difficile in, and on his overall review of, the Vale of Leven Hospital:

> Many patients were exposed unnecessarily to CDI[8] and had to suffer the humiliation and distress often associated with the infection. … A lack of strong management as well as personal and system failures contributed to the development of a culture in the VOLH that had lost sight of what is of the very essence of a hospital – a caring and compassionate environment dedicated to the provision of the highest possible level of care. The Vale of Leven Hospital Inquiry (2014), Executive Summary (p. 6)

From this report it is evident that patient safety, personal dignity, and the quality of care patients received was compromised in this hospital over the specified period of time. This inadequate care resulted in the deaths of 28 elderly people in situations of significant distress and discomfort. The experience of seeing vulnerable elderly relatives in such a state also brought considerable distress to relatives of these patients. In Lord MacLeans' words:

> It has to be emphasised that good nursing care lies at the very heart of the appropriate management of patients who contract CDI. (Vale of Leven Hospital Inquiry, P. 5)

Such sentiments echo the findings and recommendations of the Francis Reports into the failure of Mid Staffordshire NHS Foundation Trust (For example see Francis 2013, p. 76).

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[6] See Chap. 12 for an introduction to resource allocation and rationing in nursing and health care.

[7] For an introduction to organisational ethics please see Chap. 15.

[8] Clostridium Difficile infection.

These reports emphasise the vital importance of competent, engaged, and compassionate nursing to both the experience of care and, ultimately, to the survival of very vulnerable patients who find themselves incapacitated by illness, and very dependent for care and support on the strangers who are healthcare and nursing staff. In both reports the ethical and clinical domains of nursing are inextricably intertwined; as is the need for supportive organisation structures and systems to enable, challenge and engage nurses in the provision of ethically sensitive, high quality patient care.

Conclusion

This introductory chapter sets out to begin an exploration of the ethical domain of nursing practice, many elements of which will be taken up by other authors and developed in the other chapters in this book. A key point developed in this chapter is that the ethical and clinical domains of nursing overlap significantly and are deeply intertwined. Ethically sensitive, clinically competent care humanises the patient experience and is a vital element in safe effective care. However the ability to provide competent, humanising care is either enabled, enhanced or inhibited by the organisational structure and culture within which nurses practice.

The fact that nurses, and the institutions within which nurses work, can do patients/clients good or ill as persons and human beings links us directly into the ethical domain of nursing practice. It raises questions about what we, as nurses, as members of the public, and as potential patients, mean by "good nursing care". What are the similarities and differences in how we should nurse the infant who needs our care, the young child, the adolescent, the cognitively intact adult, the cognitively impaired but functioning adult, the memory impaired adult, those living with dementia, the frail elderly, the terminally ill, the dying person? The answers to these questions are at the heart of ethical, humane, competent nursing practice.

The remainder of the chapters in this book will help us explore potential answers to the questions "What is good nursing from an ethics perspective?" and "How is ethically praiseworthy nursing enacted?" within the context of particular organisations, patient circumstances and experiences. We begin by considering a number of theoretical lenses through which an examination of the ethical domain of nursing practice may be developed. We then discuss some key concepts in nursing ethics – such as personhood, autonomy and advocacy. Chapters 9 and 10 explores ethical issues at the beginning and end of life. Mental health nursing contexts give rise to some unique ethical issues described in Chap. 11. This is followed in Chaps. 12, 13 and 14 by an exploration of more specific issues such as resource allocation, fitness to practice and ethical issues in research. The book closes with a brief consideration of the emerging fields of clinical and organisational ethics.

Key Learning Points

- The ethical aspect of human behaviour refers to how we interact with and treat other people
- Nursing practice and, consequently, nursing care has an important ethical dimension
- Codes of conduct are the nursing professions collective attempt to articulate the ethical domain of nursing practice
- The nurse-patient relationship which is central to providing nursing care is also central to the ethical domain of nursing practice
- The organisations within which nurses work can enable, enhance or inhibit good nursing
- The ethical and clinical domains of nursing practice are deeply intertwined

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A Duty-Based Approach for Nursing Ethics & Practice

2

Alan J. Kearns

Abstract

The aim of this chapter is to present a duty-based approach to moral decision-making. A duty-based system of doing ethics is technically known as deontology. This chapter focuses mainly on Immanuel Kant's duty-based ethics as it is the major theory within the deontological tradition. The chapter explains some of the main features of Kant's moral philosophy and its key terms such as autonomy, dignity and respect for persons, which have become part of the parlance of nursing ethics and practice.

Keywords

Autonomy • Categorical Imperative • Deontology • Dignity • Duty • Good Will Practical Imperative

Introduction

Imagine you are driving on a motorway. You see a car stopped on the hard shoulder. A man is looking at his flat tyre. Standing behind his car are two small children, patiently waiting for him. Would you stop to see if he is alright or in need of help? If your answer is no, what would be your reason for not stopping? Do you hold a *principle* (or rule) that you never stop in such situations? Is your *principle*

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P.A. Scott (ed.), *Key Concepts and Issues in Nursing Ethics*,
DOI 10.1007/978-3-319-49250-6_2

something like the following – *I should only help those who I know*. If so, ask yourself if this *principle* is something we could follow or would like all to follow?

If your answer is yes (that you would stop), what would be your reason for stopping? Do you hold a *principle* that you always stop for such situations? Is your *principle* something like the following – *I should help others as someday I might need help from them*. If so, ask yourself if this *principle* is something we could follow or would like all to follow?

Providing a rational justification for our actions (and indeed non-actions) is central to the work of ethics. In addition, consistency of our actions in similar situations is important. For example, do you find that you might stop one day to help but, depending on how you might feel, keep going on another day? Feelings can change and moral responses based on feelings can change too. If you do decide to stop (and thus go against your feeling), is it because you believe you have a moral duty to do so?

The above reflections point to one of the most important theories in the field of ethics, i.e. Immanuel Kant's (1724–1804) duty-based approach. A duty-based approach to moral decision-making is called deontology, which is derived from the Greek word *deon* meaning duty (Gibson 2014 p. 75). Deontology is an umbrella term for ethical theories that emphasize that duty is at the heart of morality. Deontology is a non-consequentialist[1] way of doing ethics, i.e. for deontology an action is deemed to be right or wrong not because of its consequences or effects on the world but rather because it conforms to a moral law or principle. You do the right action not because of what you may achieve by it but because it is the right thing to do – it is what your duty demands.

The language of duty is often used to describe the professional and moral responsibilities of nurses, e.g. we may speak of nurses having a duty of care towards a patient irrespective of class, race or religion; a duty to respect the privacy and confidentiality of the patient; a duty to respect the autonomy and dignity of the patient; a duty to advocate for the patient and to uphold their rights. There are other duties that nurses will have, for example to their colleagues, to the respective hospital, to the health care institution, and to the community in which they work. We would generally not consider such moral responsibilities as optional but rather expect that they have a solid source or foundation that cannot be changed on the whim of individual nurses, hospitals or political policies. Therefore the language of deontology sits very well with this moral dimension of nursing.

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[1] Consequentialism is a term that describes ethical theories that base the morality of actions on the type of consequences produced. See Chap. 3 of this book for an explanation of one of the most prominent forms of consequentialism, i.e. Utilitarianism.

Kant's Deontology[2]

There are different forms of duty-based ethics,[3] yet Kant's deontology is the most prominent form. Indeed Kant has been described as the "… archetypical deontologist" (McDonald 1978 p. 7).

Good Will, Duty & Autonomy

The starting point for Kant's ethics is the concept of a good will. According to him, there is nothing unconditionally good in the world except the good will of the person (Kant 2002 p. 9). He goes on to explain that "the good will is good not through what it effects or accomplishes, not through its efficacy for attaining any intended end, but only through its willing …" (Kant 2002 p. 10). The good will is the capacity of the person to recognise and to act from a duty to follow the moral law.

In parallel to the supremacy of the good will is the experience of duty, which is a central experience in the moral life for deontology. What is important for Kant is that actions should be done not only in accordance with the moral law (i.e. actions should be right) but actions should be done from a duty to the moral law (i.e. actions should be done out of a good will) and therefore have moral worth. Kant (2002 p. 13) gives the example of a merchant not overcharging his customers. His action may be right and in conformity with his duty as a merchant as he does what is expected of him. But his action is not necessarily done from a duty to the moral law, i.e. done from the intention of wanting to act honestly. It is only in the latter case that his action can be said to have moral worth.

Kant (2002 p. 14) also gives the example of a person who has no inclination to benefit those in distress. However, out of duty to the moral law he performs an action to benefit those in distress. In this situation his action has moral worth compared to someone who may find it easy to help those who are in need. This may appear strange at first but when we think about it, if we care for someone we love, why should that action have moral worth? Surely if we showed care to someone who we do not love, that action has moral worth? The same can be said

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[2] Kant's deontology is set out in his seminal work, the *Groundwork for the Metaphysics of Morals* (*Grundlegung zur Metaphysik der Sitten*), which was originally published in 1785. This book is a prelude to the 1797 *Metaphysics of Morals* (*Metaphysik der Sitten*). There has been an abundant discussion and elucidation of Kant's work. Therefore it is difficult to capture the full depth and importance of Kant's deontology in a single chapter. Inevitably there are aspects of his ethics and philosophical insights that cannot be fully investigated and have to be set aside.

[3] Other forms of duty-based ethics include, for example, the Divine Command Theory and Rossian Ethics. The Divine Command approach would claim that actions are right or wrong because God commands that they are right or wrong and therefore we have a duty to perform (or not to perform) them. Rossian Ethics is explained on p. 25 of this chapter.

for nurses who, out of duty to the moral law, show care for people who they do not know, especially for those who are very unappreciative, difficult or even aggressive; it can be said that in such situations the actions of nurses have moral worth.

For Kant, actions that are done from duty to the moral law demonstrate the autonomy of the person. Autonomy is a key concept in Kant's system of ethics. An autonomous action is a moral action, i.e. it is an action performed because of the duty to the moral law. In nursing ethics and practice, the importance of acknowledging and respecting a person's autonomy is considered to be very important (e.g. Sasso, et al. 2008 p. 835; NMBI 2014 p. 13). Yet, there has been much discussion in the literature regarding the meaning of autonomy as a concept and as an ethical principle together with its implication for nursing practice.[4] Kant's understanding of autonomy is not based on what a person might desire but is based on reason. Autonomy is framed as self-determination by reason and morality. An autonomous action is a free action because it is directed by reason rather than by desire. For Kant, real freedom is when we act not according to our desires but according to our reason and, by extension, duty to the moral law. Freedom is shown when we act according to our duty to the moral law.

But how do we determine our duties to the moral law? We do this through the supreme principle of morality, to which we now turn.

The Categorical Imperative

Kant puts forward the categorical imperative as the supreme principle of morality (Kant 2002 p. 8). The categorical imperative is a command that is binding irrespective of how we may feel about it, whether we are inclined to follow it or not, or whether there is a direct or indirect benefit to us personally. In other words, there are no conditions attached to it, no exceptions to be made, "no ifs or buts" (Bowie 2002 p. 4).

There is one categorical imperative but various formulations of it with different emphases. The three most commonly considered are:

1. *"Act only in accordance with that maxim through which you can at the same time will that it become a universal law"* (Kant 2002 p. 37).
2. *"Act so that you use humanity, as much in your own person as in the person of every other, always at the same time as end and never merely as means"* (Kant 2002 pp. 46–47).
3. *"… act in accordance with maxims of a universally legislative member for a merely possible realm of ends…"* (Kant 2002 p. 56).[5]

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[4] Chap. 7 of this book provides a more detailed analysis of autonomy.

[5] The 'Realm of Ends' – often described as the 'Kingdom of Ends' – formulation of the categorical imperative refers to the social context of respecting persons as 'ends'. Deigh (2010 p. 169) explains that this is "… a community of all rational agents governed by laws that they give to themselves collectively."

The first formulation of the categorical imperative – "*Act only in accordance with that maxim through which you can at the same time will that it become a universal law*" (Kant 2002 p. 37) – is both a consistency test and a universal test of the principles underlying our proposed intentional actions (or what Kant describes as 'maxims'). A maxim is a principle of intentional action (Kant 2002 p. 16). For Kant, all deliberate actions are carried out in accordance with a 'maxim' (Birondo 2007 p. 265). As explained by Herbert (1999 p. 248), "a maxim is a rule of behavior that can become evident to others through the examples that one's actions set for them." The categorical imperative asks us to consider whether the maxim underlying our actions is coherent when applied to everyone and whether it can be willed to become a universal moral law.

Maxims can throw up contradictions: Firstly, there are maxims that, by definition, are contradictory when they are universally applied, and secondly, there are maxims that cannot be willed to become universal laws for everyone (Kant 2002 p. 41).[6] Kant uses the example of keeping a promise (Kant 2002 p. 39). Suppose I make a promise to pay back a loan but have no intention of doing so. Can this maxim (principle) – *I promise to repay a loan with no intention of repaying it* – be thought without contradiction if universally applied? Can I conceive of a world where such a maxim (principle) is followed by everyone? If everyone did this then the institution of promising would no longer make sense. We could conceive of a world where no one believes in promises any more so it would be pointless making a promise in the first place. Promise-making only makes sense if we believe that the person making the promise intends to make good on his/her promises. Of course, it is not completely implausible that people make promises that they do not intend to keep. Kant is, however, asking us to think of a world in which promise-making is based on a maxim of promise-breaking, which is self-defeating. To say that people break promises all the time, is not the point of the test. The test of the maxim is conceptual rather than consequential. In other words, we are not asking what would be the consequences of the action of not keeping a promise, but rather we are asking whether we can envisage a world where promise-keeping is based on a maxim (principle) of promise-breaking. Conceptually, this would not make any sense and would be a contradiction in thinking.

Another example given by Kant is willing a world in which people do not help others in need (Kant 2002 p. 40). There is no contradiction in *thinking* with this maxim when applied universally. In other words, it is possible to think of or conjure up a world in which no one helps those in need and therefore the maxim is not self-defeating (unlike with promise-breaking). However, there is a contradiction in our *willing* such a world. If we willed a world where no one would help others in need, we may actually need help at some stage and therefore we would have willed that we receive no help at that time. This would be a contradiction to our willing this maxim.

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[6] The contradictions in maxims are often referred to as a contradiction in conception and a contradiction in willing. O'Neill (1989 p. 89) uses the terms "*conceptual inconsistency*" and "*volitional inconsistency*".

The Practical Imperative

The first version of the categorical imperative provides a test for the maxims of our actions. In this way, as Timmons (2013 p. 220) explains, it is a decision-making procedure for our moral deliberation. But what is it that actually renders an action to be either morally right or wrong (Timmons 2013 p. 219)? Following Timmons (2013 p. 219), to answer this question we need to turn to the second version of the categorical imperative known as the practical imperative: "*Act so that you use humanity, as much in your own person as in the person of every other, always at the same time as end and never merely as means*" (Kant 2002 pp. 46–47).

Kant's (2002 pp. 46–47) practical imperative is probably what he is best known for. Even those who are unfamiliar with Kant's work, probably have heard of some version of this principle. It may even remind them of the Golden Rule – "so always treat others as you would like them to treat you …" (Matthew 7:12, *The Jerusalem Bible*1974). Yet, according to Kant (2002 p. 48), the practical imperative is not another version of the Golden Rule. As highlighted by Junker-Kenny (2013 p. 17), the obligation to treat a person as an 'end' is binding irrespective of whether it is reciprocated or not.

Persons are rational agents who can set 'ends' for themselves and who can autonomously follow those ends (see Korsgaard 1986 as cited in Nelson 2008 pp. 87–88). It is because persons can set 'ends' that they have worth and should be respected (see Korsgaard 1986 as cited in Nelson 2008 p. 88). As Nelson (2008 p. 104) puts it,

> we are self-governing agents. This is part of what makes us worthy of respect, and respecting rational nature is partly a matter of respecting the rational choices, the plans and intentions we and others form.

Persons can create moral laws through their reason using the categorical imperative. Persons have the ability not to be governed by feelings but to act autonomously and to dutifully follow the moral law. According to Altman (2014 p. 250), persons have the capability to act out of respect for the moral law, i.e. persons can act on moral principles. It is because persons can act from the moral law, and therefore be autonomous, that they have a special value, i.e. a dignity (Bowie 2002 p. 7). As put by Kant (2002 p. 52), "*what has a price is such that something else can also be put in its place as its* equivalent*; by contrast, that which is elevated above all price, and admits of no equivalent, has a dignity*." Persons hold an unconditional value compared to other things that can be valued (by persons) such as material goods (e.g. houses, cars, etc). Persons are irreplaceable whereas material goods are replaceable. Consider again the above example of the car stopped in the hard shoulder of the motorway. Suppose the car was involved in a crash instead and was about to go up in flames, we would do everything we could to get the man out of the car. Why? It is because we would recognise him as a person and therefore to have unique worth. Suppose his children did not survive the crash, he would be inconsolable. Although he may be put out by the loss of his car, he recognises that a burnt out car is replaceable whereas his children are not.

We are required to treat persons as ‘ends’ and never merely as a means to our ‘ends’ or to let ourselves be used as a mere means for someone else’s ‘ends’. This imperative does not mean that we may never use another person as a means to an end or allow ourselves to be used as a means to an end. For example, nurses (like most workers) are used as a means to a particular end, i.e. providing care for patients. Nonetheless, nurses are not used as a *mere* means, i.e. in an established and regulated practice, a nurse agrees to take on certain duties within a remit of a contractual agreement for a particular remuneration. By consenting to the agreed terms and conditions of employment, the nurse does not lose his or her autonomy as a person. However, should the nurse be exploited by the hospital or patients or indeed forced to carry out a task against her/his will, then she/he would be used as a *mere* means and not treated as a person.

Kant’s imperative of treating persons as ‘ends’ not merely as ‘means’ continues to provide fertile content for nursing ethics and practice. The imperative can be translated into practice as a duty (1) to respect the dignity of patients in providing care that is focused and driven by their needs; (2) to protect the privacy and confidentiality of patients; (3) to give accurate information and to communicate honestly with patients about their condition and potential treatment options; (4) to uphold the autonomy of patients and to seek their informed consent; (5) to acknowledge that patients can establish 'ends' regarding their health care – this may mean recognising that the autonomous patient may make choices that the nurse must accept, even if she/he would not recommend that course of action or indeed take it themselves. From Kant’s perspective, respecting persons entails allowing them to advance their ‘ends’ as long as those ‘ends’ do not go against the moral law.

Applying Kant’s Ethics to Nursing Practice (Including Case Study)

Let us now consider two cases below from Kant’s deontological perspective.

The Case of Lisa

Lisa Baker is a final year student nurse on placement in a busy 30-bedded ward in a general hospital. She and another registered staff nurse are looking after three of the six-bedded rooms. Shortly after coming on duty, Lisa is told by the ward manager that she is to take charge of the rooms because of staff shortages. Afterwards, she is called to deal with an emergency in one of the other rooms. This emergency takes up a lot of Lisa’s time and she struggles to attend to her own patients. A man complains that no one has checked on his wife to see how she is doing, after she had an operation a few hours beforehand. Lisa is apologetic and she knows it is unsafe post-operative practice. The same situation of being left in charge happens the next day and soon becomes a pattern. She tells the ward manager that she is not happy with this but the ward manager tells her that nothing can be done, and welcomes

Lisa to the cold reality of the health service. A few days later she has a meeting with her supervisor. She is asked how everything is going. Lisa says that everything is fine and says nothing about the poor practice.

Analysing the Case of Lisa

Let us first examine whether Lisa should tell a lie about the poor practice from the perspective of the categorical imperative – *Act only in accordance with that maxim through which you can at the same time will that it become a universal law*. If we take a possible maxim behind her action to be – *I should not tell the truth about poor practice to my supervisor especially if I think it will look bad for me* – could this maxim be willed to become a universal law?

Firstly, can the maxim of Lisa's action be thought without contradiction if universally applied? Are there any inconsistencies in thinking if the maxim of Lisa's action was to be universally applied to all student nurses? Would this lead to a conception of the world where student nurses would lie to their supervisors about issues of poor practice, especially if such practice would look bad for them. The maxim of not telling supervisors about poor practice would be self-defeating as supervisors would presume that student nurses would never tell the truth about any poor practice. If everyone did this then the institution of not telling the truth would no longer make sense. Lying only makes sense if we assume that people will normally tell the truth. If supervisors knew that students were lying, then it would be pointless in students telling lies. We could imagine a world where no supervisor believes student nurses so it would be pointless telling a lie in the first place.

Secondly, is Lisa's maxim something that could be willed for everyone, including her, to follow? Is it something that every rational person, including Lisa, really would want to follow in the long-run? Would Lisa want to will that other nurses not tell the truth in a similar situation? There would be an inconsistency in Lisa willing something that would not help her to pursue her own 'ends' – such as good health care – either as a nurse or as a patient.

From the perspective of the practical imperative – *Act so that you use humanity, as much in your own person as in the person of every other, always at the same time as end and never merely as means*, there are a number of questions that arise. For example, is Lisa being treated as an 'end' or as a 'mere means'? O'Neill (2014) makes the point that "to use someone as a *mere means* is to involve them in a scheme of action *to which they could not in principle consent*" (p. 111). It could be argued that Lisa is in some way forced to take on a responsibility that she is not yet fully qualified for. Although she reluctantly takes charge of three six-bedded rooms, she does not really consent to this action as she feels she has no choice. Therefore, it could be argued that she is being used as a mere means. Lisa also probably feels that she cannot speak out as she is still a student. Of course, one could argue that she is allowing her decision to lie to be based on possible consequences rather than pursuing the right action as a matter of duty (her action could be said not to be autonomous). If we turn our attention to the supervisor, it could be argued that by not telling the truth to her, Lisa is also using her as a 'mere means' and not as an 'end'. Following O'Neill's thought again, the supervisor cannot really consent to the actions of Lisa because she does not know the real maxim behind Lisa's actions (see O'Neill 2014 pp. 111–112). So the supervisor does not know all the facts and is happy for Lisa to proceed as normal. Her approval of Lisa is not a proper consent as she is not aware of the full situation.

The Case of Megan

Megan Gibbs is a 62 year old woman admitted to hospital with abdominal pain. Despite various tests, the doctors are so far unable to determine a cause. Megan is frustrated by this and by having to stay in hospital. One evening she decides to take some of her own tablets without the nurses' or doctors' knowledge. She is convinced that these tablets will make her better. During the night she starts vomiting and is administered an anti-nausea drug which does not seem to work. Megan takes a further two of her tablets without telling anybody. Her nausea gets worse. In the early hours of the morning, the nurses get quite concerned as they cannot explain why Megan keeps getting sick. Instead of waiting for the doctor, Megan takes another two of her tablets. When the nurses check on her, she finally discloses to the taking of the tablets. After she is assessed by the doctors, she is told not to self-medicate again. She says she did not want to disclose that she was self-medicating because she wanted to make herself better.

Analysing the Case of Megan

Let us first examine Megan's actions again from the perspective of the categorical imperative – *Act only in accordance with that maxim through which you can at the same time will that it become a universal law.* If we take a possible maxim behind her action to be – *I will not disclose that I am self-medicating to make myself better* – can this maxim be willed to become a universal law?

Firstly, can this maxim be thought without contradiction when it is universally applied? Can I conceive of a world where such a maxim is followed by everyone? There would be no point in asking patients to disclose if they are self-medicating as it would be presumed that they would not actually disclose this information. Megan's maxim of non-disclosure only makes sense if we believe that patients will disclose in the first place.

Secondly, is Megan's maxim something that could be willed for everyone, including her, to follow? The management of the health of a patient requires that the patient discloses any relevant information about their health (and perhaps lifestyle), which includes whether they are taking any medication. In order for a health plan to be effective, an honest disclosure by the patient, especially about the taking of medication, is important. Megan wants to get better but does not want to disclose that she is taking medication. However, the possibility of her health improving can only really begin once she discloses. If the maxim of non-disclosing is not good for us, how could Megan will it for any rational person to follow it?

The question could be raised as to whether Megan is autonomous from Kant's deontological perspective. On one level it could be argued that Megan's actions are signs of someone who is autonomous, in the sense that she is exercising her own self-determination regarding her decision not to disclose and what medication she wants to take. Although her choices are putting her health at risk and compromising her healthcare plan, it could be argued that she is still the one who is in charge of her own destiny.

However, if we analyse this situation from Kant's viewpoint, there are a number of observations we can make. Firstly, to be autonomous is to dutifully follow the moral law that is discerned through the categorical imperative and not to be bound by desires. If Megan is choosing to merely follow her desire not to disclose, she is in fact not acting autonomously, i.e. she is not acting freely and out of a duty to the moral law.

Secondly, from Kant's standpoint, when persons act in an autonomous way, they have dignity. It is the ability to act on maxims that square with the categorical imperative and the practical imperative that gives persons their autonomy and dignity. As put by Altman (2014 p. 30), "… we have dignity because of our autonomy …". We show our dignity as persons through our autonomous actions but these actions are moral actions founded on reason. This may be a rather different way of looking at what autonomy and dignity mean in our world today. But actions that we may deem to be autonomous may in fact not be autonomous if they do not conform to the universal moral law.

Strengths and Limitations

Kant's work has extensive influence. It is a testimony to the longevity and importance of his ideas that they are still relevant for moral decision-making in nursing practice today. The core insights of having a moral duty to do the right action, to consider the underlying principle (maxim) for our actions from a universal perspective, and not to treat persons purely instrumentally (as a means to an end) are appealing. It is a credible ethical theory that presents a systematic way of making moral choices.

However, Kant's view on lying has been a repeated point of debate as it raises some troubling issues. In essence, we have a duty to tell the truth even if it causes harm. Nurses and other healthcare practitioners are often faced with how much they should tell a patient about their diagnosis and/or prognosis. Should they always give a straight answer to a straight question? How do they strike a balance between giving someone hope and being truthful? Those unsympathetic to Kant might argue that his view of lying is not credible because we often have to tell lies to protect people. To take an extreme example, would you tell the truth to a terrorist who wants to know the location of a well-known politician? It is more likely that a person would be prepared to tell a lie to protect other people's lives.

Kant's view has also been charged with presenting a rather cold portrayal of moral living (O'Connor 2006 p. 238). It is debatable whether reason, rather than emotion, is always the best path to take in moral decision-making. Despite the fluidity and unpredictability of emotions, why can't they provide some guidance for what is the right course of action to take? In recent times, there has been a renewed sense of acknowledgment and appreciation for the role of emotion in moral decision-making, especially with the re-emergence of the virtue ethics tradition.[7]

For a duty-based system of ethics, a problem arises when we have a clash of duties. If you have a duty to care for your patient and also a duty to be truthful, what do you do if the duty to be truthful puts the patient at risk of causing self-harm? It would seem that Kant's ethics does not really help us when we are faced with a clash of duties. In *The Right and the Good*, W. D. Ross (2002) tries to address this issue of the clash of duties with the notion of *prima facie* duties. Ross makes a distinction between *prima facie* (at first sight) and actual duties which takes into consideration the situation. The *prima facie* duties consist of fidelity, reparation, gratitude, non-maleficence, justice, beneficence and self-improvement (Ross 2002). Although we must observe *prima facia* duties there may be circumstances where this is not possible. When we are faced with a number of demanding, and competing, *prima facie* duties it is the duty that has more weight that takes precedence.[8]

Kant does however allow for flexibility with some duties. There are perfect duties, which according to Kant are strict, unremitting and there are imperfect duties, which are wide, meritorious (Kant 2002 p. 42). Perfect duties must always be done without exception (Kant 2002 p. 38). Imperfect duties are still considered to be duties, however they "… have a certain latitude on how we would fulfil them" (Altman 2014 p. 101). How do we know what is a perfect duty and an imperfect duty? As we saw above, the categorical imperative requires us to consider whether the maxim underlying our actions can be thought without contradiction if it is applied universally and whether it can be willed to become a universal moral law. The maxim underlying false-promising, as we saw, throws up a contradiction in thinking when applied universally. We have a perfect duty to avoid these kinds of maxims that present a contradiction in thinking. Therefore, there is a perfect duty not to make false promises. When it comes to a maxim of not cultivating our talents (Kant 2002 p. 39), for example, there is no contradiction in thinking when applied universally. In other words, the maxim of not cultivating my talents is not self-defeating when applied to everyone. Nonetheless, the maxim of not cultivating talents cannot be willed to become a universal law. We would be willing a world where no one cultivates their talents, which would seem to go against reason and the good of the person. We have an imperfect duty to avoid these kinds of maxims that cannot be willed for everyone. As a result, the cultivating of talents would be an imperfect duty. In other words, we do not have to cultivate every talent that we have (Altman 2014 p. 101).

Conclusion

The ethical theory of deontology is an inescapable part of any formal study of nursing ethics. When we come to ethically assess actions or take decisions in nursing practice, the categorical imperative and practical imperative are very

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[7] See Chap. 4 for an explanation of Virtue Ethics.

[8] This is another form of deontology, sometimes known as Rossian, which deals with the problem of conflicting duties.

useful. We are asked to think about the maxim (principle) behind our actions: is this a maxim that can be applied to everyone else without any contradiction in thinking and is it a maxim that we would want others, and ourselves, to follow? We are asked to treat persons with respect; to treat persons as ‘ends’ and not merely as a ‘means’ because of their ability to discern the moral law and because they can act in an autonomous way by following the moral law. In the final analysis, Kant’s deontology is, and continues to be, relevant for nursing ethics and practice.

Key Learning Points

- Deontology is a duty-based approach to moral decision-making.
- Deontology is a non-consequentialist theory of ethics: You do the right action not because of what you may achieve by it but because it is the right thing to do – it is what your duty demands.
- Kant’s deontology is the most prominent and influential form of duty-based ethics.
- Central concepts of Kant’s deontology include: (A) Good Will, (B) Duty, & (C) Autonomy
  - (a) Good Will: the will of the person to act from a duty to follow the moral law;
  - (b) Duty: Actions should be done from a duty to the moral law;
  - (c) Autonomy: Self-determination governed by reason and morality.
- Categorical imperative: the supreme principle of morality. Different formations include:
  - (a) *“Act only in accordance with that maxim through which you can at the same time will that it become a universal law.”* (Kant 2002 p. 37).
  - (b) *“Act so that you use humanity, as much in your own person as in the person of every other, always at the same time as end and never merely as means*.” (Kant 2002 pp. 46–47).

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Utilitarianism as an Approach to Ethical Decision Making in Health Care

3

Heike Felzmann

Abstract

This chapter outlines core characteristics of Utilitarianism and explores them with regard to their significance in healthcare settings. It presents Utilitarianism as characterised by the following five features: (1) consequentialism, (2) welfarism, (3) equality of moral status and impartiality, (4) maximisation, (5) aggregation. It explains the theoretical underpinnings of each of these characteristics, while illustrating them with regard to issues arising in the nursing and wider healthcare context. The chapter concludes with an outline of common themes and considerations in Utilitarian writings with significance for nursing and healthcare practice.

Keywords

Utilitarianism • John Stuart Mill • Nursing Ethics

Introduction and Case Study

Resource Allocation for Rare Diseases

Cystic Fibrosis (CF*) is a chronic and progressive genetic disease that affects lung function and the digestive system. It is a rare disease with around 70,000 sufferers globally. Due to its genetic basis some geographic areas, such as Ireland, have a particularly high incidence. A range of specific genetic defects are responsible for the creation of sticky mucus which obstructs the lungs of* CF *sufferers and lead to shortness of breath,*

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P.A. Scott (ed.), *Key Concepts and Issues in Nursing Ethics*,
DOI 10.1007/978-3-319-49250-6_3

frequent lung infections and digestive problems. Over time, the lung function deteriorates and ultimately leads to premature death, with a median age of death of CF *sufferers in Western countries in their late 30s. Treatment for* CF *has improved significantly and quality of life and survival times of* CF *sufferers have extended continuously over the last few decades; however, no cure has yet been developed. Given the level of impairment and the expectation of premature death of* CF *sufferers, the development of a drug that promised to target specifically the underlying defects of the disease, rather than merely the symptoms of the disease, in a small subgroup of* CF *sufferers was welcomed enthusiastically. The company Vertex brought ivacaftor (Kalydeco) to market in 2012, a drug that promised to provide such a sustainable treatment. The drug is suitable for those* CF *sufferers who have a specific genetic mutation in the cystic fibrosis transmembrane conductance regulator (CFTR), around 5% of all* CF *sufferers. Its initial cost in the US was 300,000 USD per patient per year. This means a significant cost for the healthcare system, albeit for a very small number of patients. Should this drug be covered by the public healthcare system?*

There are different possible responses to this question. Many health care professionals would state that a medication that has a chance to significantly improve the management of a life threatening condition should be provided to patients suffering from that condition, no matter what its price is. In contrast, the theory of Utilitarianism proposes to engage with this question primarily on the basis of assessing and comparing consequences of different alternative options. Utilitarianism considers the overall costs and benefits of the use of the medication and compares it to the overall costs and benefits of other possible options. From a Utilitarian perspective, what needs to be considered is the question whether the benefit to CF *sufferers, from this drug, is sufficiently high to justify the expense, and whether other ways of spending the money, for other patients or on other aspects of care, might have potentially better consequences overall.*

In the following, the Utilitarian approach will be introduced in more detail and important characteristics of the approach will be explored, drawing on examples for its application to issues arising in the health care setting.

History and Core Characteristics of Utiliarianism

Utilitarianism is one of the “big three” traditional moral theories, together with Deontology and Virtue Ethics. Like any of these theories, Utilitarianism has received enthusiastic endorsement as well as trenchant criticism. In assessing the value of Utilitarianism as an ethical theory for health care, it is important to consider carefully what it entails.

Utilitarianism is a theory that was originally developed in the Enlightenment period when many theorists were expecting scientific insight to change human life for the better. Utilitarianism exemplifies this optimism about the role of science for morality. Jeremy Bentham (1748–1832), one of the founders of Utilitarianism, believed that Utilitarianism could provide a science of morality that could be used for the betterment of human life. He addressed a large number of social issues from a Utilitarian perspective, from law-making to prison reform. His writing was characterised by a strong belief in precision and differentiation – for example in his discussion of pleasures and pains in his *Introduction to the Principles of Morals and Legislation* (1789) he distinguishes between 14 types of pleasures, 12 types of pain, and over 30 types of influences on the experience of pleasure. Incidentally, Bentham's belief in the importance of science extended to the treatment of his body after his death: he donated his body to science to University College London, where it was kept embalmed in a show cabinet.

A student of Bentham, John Stuart Mill (1806–1873), wrote the most well-known introduction to Utilitarianism, a small book simply entitled *Utilitarianism* (1861) in which he explained the core assumptions of Utilitarianism. When Utilitarianism was first proposed it encountered similar criticisms as today and was criticised as a theory that misunderstands the nature and depth of our moral obligations. Critics of utilitarianism in the health care field sometimes argue in a similar vein that the duties and obligations of healthcare professionals to help their patients are absolute, and that a theory that weighs up costs and benefits of different options rather than endorsing absolute requirements does not do justice to the moral duties of health care professionals. In response to similar criticisms at the time, Mill wrote his book as a defence of Utilitarianism as a theory that is indeed capable of doing justice to our deepest intuitions about morality.

Utilitarianism defines the morally good as the achievement of "the greatest good for the greatest number". Its core ethical principle is the "principle of utility":

> By the principle of utility is meant that principle which approves or disapproves of every action whatsoever, according to the tendency which it appears to have to augment or diminish the happiness of the party whose interest is in question: or, what is the same thing in other words, to promote or to oppose that happiness. (Bentham 1789/2010, I.2., pp. 6–7)

Utilitarianism in the tradition of John Stuart Mill has a number of core ethical characteristics:

1. Positive or negative consequences are the most important features for assessing the moral quality of a situation (consequentialism)
2. Effects on an individual's experiences, interests and well-being are the kinds of consequences that count, especially the avoidance of pain and suffering and the increase in pleasure and happiness (welfarism)
3. Every individual who is able to have certain types of positive and negative experiences or interests should count equally (equality of moral status and impartiality)
4. There is a moral obligation to maximise overall benefit, by counting up the overall consequences and choosing the option with the highest overall benefit (maximisation)
5. Moral quality is determined by aggregating consequences across all affected individuals who can experience positive and negative experiences; Utilitarianism aims for the achievement of the best overall aggregate result across individuals (aggregation)

These core characteristics will be discussed, one by one, in the sections which follow. The main aim of this discussion is to identify and explain criticisms that have been levelled against Utilitarianism and explore whether Utilitarianism can address these criticisms. While the implications for the health care context will be considered throughout, this discussion may nevertheless seem quite theoretical, but it will help define more clearly what exactly Utilitarianism stands for.

Consequentialism

The focus on consequences in Utilitarianism distinguishes Utilitarianism fundamentally from the other big theories of ethics. In Utilitarianism, it is the good or bad consequences that determine whether something is right or wrong. In the short case study on CF and the drug Kalydeco above, relevant consequences are the money spent due to the costs of the medication (which will not be available to other patients once spent) in relation to the benefits of the drugs for the CF patients. In contrast to Utilitarianism, deontological theories identify commands and prohibitions that are determined as binding without regard to consequences.[1] Similarly, Virtue Ethics is concerned with the practical realisation of good character traits for which consequences are at most indirectly relevant, for example if the assessment of consequences happens to be an important feature of the situationally relevant character trait.[2]

An important distinction in Utilitarianism is whether it should be concerned with the consequences of individual actions (a position that is called Act Utilitarianism) or with the overall consequences of having particular rules (a position that is called Rule Utilitarianism). When considering the example of the CF drug, Act Utilitarianism would ask the individual health professional to consider, for each patient, whether the likely health benefits for this patient are sufficiently positive to merit the cost of the drug. In contrast, Rule Utilitarianism would focus on developing general rules to apply in such cases, regardless of the very specific features of every individual case. In the case of Act Utilitarianism, the individual is responsible for assessing and comparing the likely consequences of their potential actions. In the case of Rule Utilitarianism, the focus is on decisions about the most advantageous rules to follow for society. Decision-making about the best utilitarian rules is left to experts who have the authority and power to implement rules in society, for example by means of laws, education or incentives. In the case of nursing, the implementation of Utilitarian values would thus lie mostly in the hands of the Nursing Bodies who determine the values and rules of the Nursing Codes of Conduct and who determine how nurses are educated. Individual nurses would primarily be expected to apply those rules rather than make Utilitarian calculations about likely consequences themselves.

In general, Utilitarianism highlights that the consequences of our actions are important for how we understand the morality of our actions. The same action might

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[1] For a discussion of Kantian ethics, one of the most significant deontological ethical theories, please see Chap. 2.

[2] Chapter 4 provides a discussion on virtue ethics and nursing practice.

be right in one context, but wrong in another context. So killing a person might be considered wrong by Utilitarianism when it ends a life that would have been characterised by more pleasure than pain whereas it might be considered right under some circumstances if it ends a life that would otherwise have been characterised by terrible pain. That the vast majority of persons takes consequences to be at least somewhat important for morality can be seen in our rejection of at least some absolute demands of moral duties, even in the face of catastrophic consequences. Famously, the deontologist Kant was of the opinion that a person should never lie, even if telling the truth will lead to a friend's death, whereas lying would have save his life. For a Utilitarian, consequences would have a significant impact on whether a lie would be ethically justified or not.

Whether Utilitarian consequentialism is a convincing moral position depends on how significant we consider consequences to be, and in particular whether we assume that it is ultimately possible to explain all moral obligations on the basis of consequences. With regard to the practice of nursing, Utilitarianism would assume that the core values of nursing can all be explained by the effects that decisions have on patients, families, health professionals, or other stakeholders. In assessing the value of Utilitarianism for nursing, one needs to reflect on whether that appears to be an accurate depiction of the values of nursing.

Welfarism

Classic or traditional Utilitarianism assumes that the consequences that matter ethically are the impacts on an individual's experiences and well-being, especially the avoidance of pain and suffering and the increase in pleasure and happiness. This focus on pleasure and pain as core moral characteristics in traditional Utilitarianism was met with scepticism from the outset. Many philosophers have understood morality as a function of the "higher" aspects of human nature, for example rationality or religious faith, while considering bodily or emotional characteristics of human beings to be a "lower" aspect that does not represent what is essential about human beings. In contrast, Utilitarianism appears to focus on the sensory or bodily characteristics of pleasure and pain as core moral features, and thereby on exactly those "lower" features. Accordingly, critics said that Utilitarianism was a theory not adequate for rational and spiritual human beings.

In response to these criticisms, Mill himself introduced a distinction between higher and lower pleasures. He stated that we experience pleasures and pains also with regard to other realms of our experience, such as intellectual or cultural pleasures which he identified as "higher" types of pleasure. Mill argued that the higher pleasures were actually considerably more valuable than the bodily pleasures, and famously stated that:

> It is better to be a human being dissatisfied than a pig satisfied; better to be Socrates dissatisfied than a fool satisfied. And if the fool, or the pig, are of a different opinion, it is because they only know their own side of the question. The other party to the comparison knows both sides. (Mill 1861/2008, Ch.2, p. 7)

It can certainly be questioned whether this lower ranking of bodily pleasures and pains is convincing, especially from a nursing perspective that is so closely familiar with how intertwined bodily, mental and social aspects of human life are.

However, the more general core point for Utilitarian ethics is the focus on human welfare which takes the experience of human pleasures and pains to be essential for our ethical decision-making. It could be argued that such a focus encapsulates core values of nursing with its holistic approach to human health and human experience. Unlike more abstract and rationality focused theories like Kantian Deontology, Utilitarian theory allows the appreciation of the variety of human experiences, from bodily pain, pain relief or the pleasure of bodily comforts, to psychological suffering and discomfort or the enjoyment of activities, to the pains of loneliness or the pleasures of company and social integration.

Equality of Moral Status and Impartiality

Utilitarianism is a theory that, despite some of the problems that will be discussed in the following sections, takes impartiality seriously. Jeremy Bentham famously characterised Utilitarianism as demanding "[e]veryone to count for one and nobody for more than one". He assumes that pleasures and pains should count the same no matter who experienced them. While this might sound obvious at first sight, especially from today's point of view, at the time strict social hierarchies meant that it was unusual that persons from different walks of life should be considered equally. For example, John Stuart Mill was considered revolutionary in his claims in *On the Subjection of Women* (Mill 1869) that women should be assumed to be as rational and cognitively able as men, and should be treated equally to men with regard to important rights, like having the vote or having access to the same educational opportunities as men. He also drew on Utilitarian thinking in his condemnation of slavery. Even more recently, Utilitarianism has been notable in drawing attention to the neglect of global inequalities in ethics and the importance of avoiding suffering in the developing world, no matter how distant the problem might appear. Similarly, among the strongest proponents of animal rights have been Utilitarians like Peter Singer who have argued that animals that can experience pleasure and pain have moral significance, and our social practices around animals need to be changed to take account of this.

However, this focus on the equality of consideration of those who can experience pleasure and pain also has a flip side which is particularly important for the healthcare context. What about those human beings who are not able to have such experiences? Famously, Peter Singer argued that there should be the option of euthanasia for some newborns with significant cognitive disabilities that impair their ability to have certain kinds of experiences and interests. This position is based on the assumption that they are not equal to human beings with full experiential capacities, due to their significant impairments and therefore did not meet the criteria for moral significance. Singer has been strongly criticised for his position. Especially in a nursing context, such a position is potentially troublesome, given that many nurses regularly care for patients who are in conditions, such as profound cognitive disability, severe dementia or persistent vegetative state. A position that does not consider these patients as deserving of an equal level of care appears to be highly problematic and goes against the fundamental values of nursing.

Maximisation

Utilitarianism is a theory which is focused on the maximisation of positive consequences and the minimisation of negative consequences. To follow the demand to maximise overall benefit has at the very least intuitive appeal. If we have a choice of several options, it appears obvious that the option with the most positive consequences is preferable to options with less positive consequences. But does that mean that it is appropriate not to buy the expensive CF drug and rather spend the money on other cheaper interventions that will have cumulatively better consequences? A Utilitarian would answer yes to this question.

There are a number of problems related to Utilitarian maximisation. First of all, if you want to maximise positive consequences, how exactly do you do this? How can you judge different types of consequences on a single scale of goodness? This is sometimes called the problem of "commensurability". A traditional Utilitarian needs to assume that ultimately all experiences of pleasure and pain can be quantified on a single scale, and that different potential consequences can be assessed with regard to how much benefit they bring about. With regard to the healthcare context that would mean, for example, that you can compare the experience of pain from an operation with the impairment in life quality arising from asthmatic shortness of breath, or the experience of alleviation of symptoms of depression, the relief of receiving a negative test for a serious condition, the recovery from a debilitating illness, or the pleasure of a friendly conversation, all by assigning a certain positive or negative value to each that makes them comparable across each other in a quantifiable way.

This is the theory. But even if we assume that this works in principle, how exactly can we make such judgments in practice? The Utilitarian position demands that we decide to maximise overall benefit by comparing different options. In the case of Act Utilitarianism such assessment requires consideration of all possible consequences in a particular situation where a decision needs to be made. This raises a number of practical problems: How do we know what the likely consequences are, given that we are notoriously bad at predicting the future? How far into the future are we supposed to go? How widely do we need to consider likely effects on different stakeholders? How do we not just capture, but also accurately assess the overall benefits of each of the different identified options? For example, imagine making a decision on how to engage with a patient who refuses to cooperate with treatment while their family pressures the patient to conform with the suggested treatment. Utilitarian decision-making would have to take into account the likely health and emotional consequences of the patient cooperating vs refusing to cooperate; the likely interpersonal and health consequences of the nurse actively intervening in either direction; the likely consequences of family being ignored or brought in; the potential consequences within the team of the nurse taking a particular course of action; the longer term consequences for trust of the patient in the healthcare system etc. And this is only a small subset of considerations that proper Utilitarian reasoning would need to take into account. As human beings we are significantly cognitively limited; Act Utilitarianism in particular appears to be an incredibly demanding approach. This is one of the reasons why Rule Utilitarianism has been proposed, assuming that it is more feasible for an individual to follow a limited number of rules, and also that it is more feasible to identify rules that are likely to be beneficial overall.

The Utilitarian demand for maximisation however goes even further, in that it can be used to compare the ethical desirability of certain "types of life", associated with the ethical obligation to choose those lives that are characterised by the most positive consequences overall. To illustrate the issue, Crisp (1997) provides the example of "Haydn vs. Oyster" :

> You are a soul in heaven waiting to be allocated a life on Earth. It is late Friday afternoon, and you watch anxiously as the supply of available lives dwindles. When your turn comes, the angel in charge offers you a choice between two lives, that of the composer Joseph Haydn and that of an oyster. Besides composing some wonderful music and influencing the evolution of the symphony, Haydn will meet with success and honour in his own lifetime, be cheerful and popular, travel and gain much enjoyment from field sports. The oyster's life is far less exciting. Though this is rather a sophisticated oyster, its life will consist only of mild sensual pleasure, rather like that experienced by humans when floating very drunk in a warm bath. When you request the life of Haydn, the angel sighs, 'I'll never get rid of this oyster life. It's been hanging around for ages. Look, I'll offer you a special deal. Haydn will die at the age of seventy-seven. But I'll make the oyster's life as long as you like... (Crisp 1997, p. 24)

According to traditional Utilitarianism, the oyster with its infinite life will ultimately accumulate more pleasure overall than Haydn with his full human life. Accordingly, it can be argued that a Utilitarian would have to choose the oyster over Haydn, a choice that few people would probably make when choosing between both options. What this example indicates is that if a single quantitative measure is applied, maximisation can end up with strange results that do not appear particularly desirable.

However, this idea of assessing the overall quality of a life is perceived as a positive feature by many Utilitarians, as it might help make treatment and intervention decisions, especially when there are resource constraints. However, non-Utilitarians would highlight that such an attitude of assessing the quality and worthiness of whole lives could be considered to be profoundly paternalistic, arrogant, and demeaning. Especially in a nursing context, to make judgments with regard to patients on whose lives are more worthy of intervention than others would appear to go against the fundamental demand of treating every patient with equal care and respect.[3]

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[3] For a discussion of resource allocation and rationing in the context of nursing care please see Chap. 12.

Aggregation

The Utilitarian demand for maximisation is a demand for maximisation of benefits across all affected individuals; that means it understands moral decision-making as by its very nature addressing and affecting a wider group of people. With this focus, it differs to some extent from deontological and virtue ethics approaches which in the healthcare ethics context tend to be focused on the relationship of the healthcare professional and patient rather than considering a wider range of stakeholders.

Bentham (1789) understands community to be *“the sum of the interests of the several members who compose it”* (I.4, p. 7); the impact of moral actions needs to be considered with regard to all those who are going to be affected by those actions. This highlights what could be seen as both a particular strength and particular problem of the Utilitarian approach. On the one hand it shows its sensitivity to the importance of considering a wide range of stakeholders when thinking about the morality of actions. This is linked to the Utilitarian goal of improving society for the better through Utilitarian interventions. Both Bentham and Mill were actively engaged during their lifetime in trying to achieve social and legal reform to improve lives in society on the basis of Utilitarian principles. On the other hand, this reform enthusiasm also comes with the potential problem of promoting changes that might be contrary to popular concerns, and perhaps being overly quick in endorsing change, without due regard to the more complex and unpredictable longer term consequences that might arise from social changes in the name of increasing overall utility.

One particular challenge that Utilitarianism encounters with regard to aggregation across persons is related to the issue of justice. On the one hand, it does propose a solution to the question of distributive justice, by proposing a cost-benefit approach to the question of how to distribute scarce resources among a population. Utilitarian approaches propose that resources should be distributed in a way that you obtain the most utility from your resources across the population, such as is illustrated by the CF drug example. This is to some extent what organisations like NICE, the UK National Centre for Clinical Excellence, are doing: they evaluate health care products and interventions with regard to how much they cost and how much benefit they are going to achieve for that cost. Only interventions that achieve a sufficiently high cost-benefit ratio based on available evidence are going to be approved by NICE. When distributing resources a Utilitarian approach would draw on such evidence to compare which potential healthcare interventions are most effective in bringing about benefit, and will choose those which are more effective in bringing about benefit.

For example, in the case of the CF drug, it is not sufficient that it has a substantial benefit, but the benefit must be sufficiently high to be proportionate to the money spent. While Kalydeco has been approved by NICE and is being covered by many payers, a newer CF drug combination by the same company that is targeted at a different subgroup of CF sufferers, the combination of Ivacaftor/Lumacaftor (Orkambi), has come on the market with a similar price tag. In contrast to Kalydeco, the new drug has not been recommended by NICE, because its beneficial effects appear to be comparatively small in relation to its price.

While such an approach certainly matches some of the intuitions that we have about how healthcare resources should be distributed, it also has some significant problems. In particular, aggregation across individuals raises problems with regard to the treatment of minorities. One of the probably most well-known concerns about Utilitarianism is that Utilitarian reasoning might justify treating minorities badly due to the lower impact on overall utility that their bad treatment would have. In the healthcare context, a Utilitarian approach to the distribution of resources is likely to disadvantage some minorities, especially those that require particularly costly treatment or care for their health conditions, such as persons with rare diseases for whom medication can often be extraordinarily expensive. They may have significant health needs and be particularly vulnerable, but on the Utilitarian model their case may not merit expenditure if compared to other groups, as the benefit derived from the intervention is too small in comparison to its cost.

Strengths, Limitations and Contributions of a Utilitarian Perspective for Nursing and Healthcare Practice

Utilitarian approaches are used quite commonly in bioethics, and some of the most well-known bioethicists internationally are Utilitarians. Utilitarians have been particularly influential in the reflection on the use of new or future technologies, often endorsing more technology-friendly views and being more optimistic about their potential to change society for the better. In contrast, deontological and virtue ethical theories tend to take more cautious positions. Utilitarianism has also been influential in relation to addressing issues of wider societal concerns, for example issues of global justice or animal rights. With regard to questions of healthcare delivery, Utilitarian discussions have been particularly prominent in some of the following areas:

1. End of life decision-making: Utilitarians have been arguing against the distinction between killing and letting die with regard to the question of euthanasia and assisted suicide (Glover 1990). They have argued for the importance of considering the suffering experienced by persons in end-of-life situations where medical decisions to "let die" without causing death may cause significantly more suffering than an active intervention would (Rachels 1975).[4] Utilitarian authors have also highlighted the importance of quality of life measures for treatment decisions, including the argument that if a foetus – or even, in some cases, a newborn – has a condition that will not allow them to have sufficient capacities and quality of life, then it might be ethically permissible to end their life (Kuhse and Singer 1985; Singer 1993).
2. Reproductive decision-making: Utilitarian authors have argued for the permissibility of a wide range of reproductive interventions, from abortion to the use of new technologies. They have supported the use of a variety of interventions to

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[4] For further discussion of ethical issues at the end of life please see Chap. 10.

allow parents new choices with regard to their embryos, including allowing saviour siblings (Alghrani and Harris 2006). They have also supported the use of pre-implantation genetic diagnosis (PGD) to avoid implanting embryos with genetic diseases, or even more controversially, the selection of children on the basis of non-disease characteristics during IVF (Savulescu 2001).[5]

3. Human enhancement: Utilitarians have been widely supportive of enhancements, which is the use of healthcare interventions not for treatment but for improvement of persons within the normal range to improve specific characteristics about themselves (Harris 2010; Savulescu and Bostrom 2009). Enhancements drawing on existing health care interventions include, among others, doping (Foddy and Savulescu 2007) or cognitive enhancement, for example by means of Ritalin (Greely et al. 2008).
4. Research involving embryos: Utilitarians have argued for the importance of advancing research to cure diseases. They have supported the use of embryonic stem cells in research, on the basis of the argument that this research appears to have the best chance of obtaining positive results (Harris 2004). They have also supported the use of cloning in embryo research, under restricted circumstances.
5. Research participation: Utilitarians have argued for the obligation of all patients to participate in research in order to widen the evidence base for evidence-based medicine and improve the available knowledge base (Harris 2005).
6. Resource allocation: Utilitarians have argued that the application of the principle of utility means that resources in the healthcare system should be allocated on the basis of obtaining the most utility for the costs spent. Cost benefit analysis is a basic health economic technique and is based on Utilitarian reasoning (Torrance 1987). It can be applied to all areas of healthcare resource allocation. One area where the role of Utilitarian principles for allocation decisions have been discussed extensively is in the area of organ transplant decisions (Persad et al. 2009). Particular problems are also raised by assumptions of some Utilitarians that lives of individuals with cognitive disability are less valuable than those of cognitively normal individuals (Vehmas 1999).

Conclusion

Utilitarians have not been shy in taking controversial positions with regard to healthcare and research. Opinions among healthcare ethicists on Utilitarianism are strongly divided. On the one hand, the basic Utilitarian assumption that consequences matter morally clearly has appeal for healthcare professionals, whose job largely consists in trying to make a positive difference to their patients' lives. Utilitarianism acknowledges that patients' experiences need to be taken into account to understand the moral significance of healthcare delivery. Utilitarianism also insists that moral decision-making does not merely take place between a patient and a healthcare professional but that a wider range of stakeholders need

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[5] For further discussion of ethical issues at the beginning of life, including issues of abortion, pre-implantation genetic diagnosis and saviour siblings, please see Chap. 9.

to be taken into account. In particular, it addresses the pressing issue of decision-making on resource allocation under resource constraints.

On the other hand, in everyday healthcare decision-making Utilitarianism is not easily applied, given the complexities of the practical assessment of consequences. In contrast, deontological and virtue ethical decision-making provide more easily applicable guidance. Utilitarianism also does not fully acknowledge the specific ethical qualities of caring relationships in which the healthcare professional has a particular responsibility towards each individual patient, to safeguard their vulnerability and dignity. The application of Utilitarian reasoning in resource allocation contexts in particular shows little consideration for the specific needs of each individual.

Key Learning Points

- Utilitarianism is a moral theory that focuses on the overall balance of positive and negative effects of a healthcare professional's actions; all actions are considered on the basis of consequences, not on the basis of fundamental moral rules and principles or with regard to character traits.
- Utilitarianism, as an approach, can be particularly helpful when considering decisions in which the quality of patients' experiences as well as the impact of decisions on other stakeholders is at issue.
- Utilitarianism as an approach is also often used when making decisions on the allocation of resources, especially with regard to the use of cost-benefit reasoning.
- Utilitarianism tends to be open to substantially changing existing human practices and, for example, allowing the use of new and controversial technologies if there appears to be a substantial likelihood of overall positive consequences.
- Utilitarianism has been criticised for not acknowledging the absolute dignity of human life, for example in the context of disability rights or end-of-life decision-making.
- Utilitarianism advocates for decision-making that looks at whole population groups over individuals, and might at times leave certain individuals or groups worse off in order to use resources to achieve a greater benefit for a larger number instead.

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Virtue Ethics and Nursing Practice

4

Derek Sellman

Abstract

Virtue ethics is an approach that focuses on character with the assumption that a person of good character will tend to behave in ways that are consistent with their character. A virtue ethics for nursing is therefore concerned with the character of individual nurses and seeks ways to enable nurses to develop character traits appropriate for actions that enhance wellbeing. This chapter offers some insights into the nature of virtue ethics from an Aristotelian perspective and includes an outline of the virtue of *phronesis* (practical wisdom) which provides guidance in situations where it is not obvious what action would be the virtuous action. Virtue ethics is contrasted with modern ethical theory (deontology and utilitarianism) and some ways in which virtue ethics can enhance professional nursing practice are considered.

Keywords

Virtue • Aristotle • Kindness • Compassion • Phronesis (Practical Wisdom) Nursing

Introduction

This chapter is about the idea of virtue ethics. In recent times virtue ethics has come to be considered as one of the big three ethical approaches alongside deontology and utilitarianism. However, virtue ethics has made fewer inroads into applied and professional ethics because *"… unlike deontological theories*

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P.A. Scott (ed.), *Key Concepts and Issues in Nursing Ethics*,
DOI 10.1007/978-3-319-49250-6_4

or consequentialist theories, virtue theory is not geared toward answering specific questions, or making specific ethical decisions" (Lachman 2006 p. 10). If this is true then it might be reasonable to ask what it is that virtue ethics can offer nurses as they go about their everyday practice. The short answer is that, at a minimum, virtue ethics can help to redirect focus away from mere rule following towards consideration of what counts as good for human beings. It does so by encouraging the cultivation of those character traits that promote actions that are fair, honest, kind, compassionate and so on; actions that contribute to human wellbeing. Thus, virtue ethics might be described as an approach that preempts the specific questions and specific decisions to which Lachman (2006) refers.

At the outset we should recognise that virtue ethics is not one thing but rather can be understood as an umbrella term for sets of ideas that share a common foundation. In this respect virtue ethics does not differ from other ethical approaches including but not limited to deontology and utilitarianism; there are factions in both of those theories that diverge in regards to particular points and interpretations. Nevertheless, as is commonly understood, there are some fundamental premises that underpin different versions of both deontology and utilitarianism, and the same can be said for virtue ethics. If the deontologist is characterised as claiming that an act is good if it is in accordance with duty and the utilitarian is characterised as claiming that an act is good if it brings about the best consequences, then the virtue ethicist might be characterised as claiming that an act is good if it is a virtuous act. These characterisations are, of course, over-simplifications and while it is not the purpose of this chapter to discuss deontology or utilitarianism,[1] both theories will be mentioned in order to help explain some of the nuances of virtue ethics and how it differs from those two theoretical approaches. The essential point here is that just as there are different versions of deontology and utilitarianism, so there are different versions of virtue ethics.

The one thing that underpins virtue ethics is the emphasis on character; and this focus on the character of the agent is what distinguishes virtue ethics from most other approaches to ethics.[2] Some versions of virtue ethics characterise this difference as a difference of the primary question: so that whereas most ethical theories seeks to answer the question 'what should I do?' virtue ethics asks instead 'what type of person should I be?' This distinction suggests either that what a person does is less important than how a person is, or that virtue ethics does not provide action guidance. Neither suggestion is as straightforward as critics claim, and, as will be outlined in this chapter, both oversimplify many of the ideas about virtue ethics. Danielle's experience, described in the case-study below, is illustrative and will be referred to throughout the remainder of this chapter in order to explore some key elements of virtue ethics.

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[1] Chapters 2 and 3 in this book are dedicated to the theories of deontology and utilitarianism respectively.

[2] One exception is 'the ethics of care' or 'care-based ethics' which forms the focus of Chap. 5 in this book.

Case-Study

Danielle is a third-year student nurse half-way through her final clinical placement on Azalea ward, a busy surgical unit. Like all student nurses she has had a mentor in each of her previous placements but she has never before met anyone quite like Belanna, her mentor on Azalea ward. It is a very busy ward, yet unlike most of the other qualified nurses Danielle has worked with, Belanna seems always to know what to do whatever the situation. She always has a kind word to say to everyone from the most difficult and demanding patient to the most arrogant and obnoxious of doctors; from the ward cleaner to the hospital chief executive, and even in the most challenging of situations she always seems to be able to find a way to ensure that everyone's dignity is upheld, that no one gets left unattended, and that no one feels neglected or humiliated. Belanna is kind, compassionate, and caring but does not flinch from confronting situations that might otherwise undermine those ideals of practice. Yet she has no pretentions and does not think that what she does is anything special, in fact she thinks that she does not do anything different from that which anyone in her position would do. She is always seeking feedback from students, patients, families, and co-workers and goes out of her way to ensure that everyone who arrives on Azalea ward has a positive experience. At first Danielle thought that this was too good to be true, or that it was all an act that would collapse at the first sign of frustration but after 6 weeks on the placement, Danielle recognises that there is something about Belanna that marks her out as a particularly good nurse. Danielle decides that Belanna represents the type of nurse that she (Danielle) wants to become.

What Is Virtue Ethics?

So what is virtue ethics? Virtue ethics is the term given to an approach that has a focus on character. More specifically, it focuses on the character of the actor or agent. Hence virtue ethics is sometimes referred to as agent-based ethics. This is to be contrasted with act-based ethics in which the primary focus is on the act. As noted earlier, act-based ethics asks the question: 'what should I do?' while agent-based ethics tends towards asking: 'what sort of person should I be?' – although it should be noted that not all versions of virtue ethics make this distinction. Armstrong (2007), for example, claims an action-oriented account of virtue ethics for nursing while Crisp (2007) and Hursthouse (1997) both hint that the latter question is subsumed within the former and so engage seamlessly with action guidance in their accounts. A more nuanced distinction might be had by noting that act-based theories tend towards accounts in which action is in accordance with an external principle or from a rule derived from a general principle, while agent-based approaches tend to emphasize the role of character in formulating decisions for actions. So the deontologist may ask, 'which duty takes precedence in this situation?'; the utilitarian may ask 'what action will lead to the best consequence?' and the principlist may ask 'which principle applies here?' In contrast, guidance for action in agent-based ethics requires the agent to seek to become a certain sort of person, a person with the virtues to lead them to act in ways that the virtuous person would act. So, following Hursthouse (1997), the virtue ethicist might ask ‘if I act in such and such a way, would I be acting in a way that was virtuous?’ The assumption here is that by becoming, for example, a just, courageous, and honest person, the individual will tend towards acting in just, courageous, and honest ways out of habit or inclination. This is to say that the just, courageous, and honest person will act in ways that reflect their character. And this is exactly what Danielle is witnessing when she sees her mentor (Belanna) in action. The reason Belanna seems to know what to do whatever the situation is that she is a kind, compassionate, honest, just, and courageous person and this is exemplified in her actions. Belanna acts in ways that reflect her character.

It is often said that people act characteristically. That is, we expect people to act in ways consistent with the type of person we take them to be. We tend to identify friends, colleagues, and peers in terms of their characteristics. We all know people who we can describe as kind or honest or courageous and the more they continue to act in ways that are kind and honest and courageous the more we appreciate and admire their integrity and their character. Similarly, most of us can identify individuals who might be described in more negative terms; we might thus identify some people as tending towards dishonesty, ruthlessness, unhelpfulness, unreliability and so on. Many of Danielle’s earlier mentors, while not particularly dishonest or unkind, did not seem to possess the same confidence in being the type of nurse who acts, as Belanna does, by inclination in kind or honest ways. Most of Danielle’s earlier mentors did aim to do the right thing but sometimes doing the right thing seemed to require them to follow rules or general guidance. Of course, general rules are helpful but at times merely following the rules seemed to result in nursing actions that might be perceived as, if not exactly unkind, then at least less than kind or less than compassionate. Danielle has a vivid recollection of the distress experienced by a young patient when informed of the death of her husband in the car accident in which they had both been involved. Danielle has often wondered if being told the truth in the matter-of-fact manner in which the news was delivered was a kind thing to do, but she had been told that being honest was a requirement of both the nurses code (NMC 2015) and of the principle of respect for autonomy (justified on the grounds that a patient has a right to know the truth if they are to make autonomous choices). Having now seen the way in which Belanna is honest in her dealings with patients, relatives, and others while at the same time being compassionate and kind is leading Danielle to question whether what she has been told previously about ethical practice is altogether accurate or satisfactory. Danielle is now beginning to recognise that being honest is only one part of ethics. The need to act in ways that are not callous or unkind means that honesty cannot be seen in isolation from other aspects of ethical nursing practice. And the more she watches Belanna’s practice, the more Danielle wants to be like her, and the more she recognises that Belanna acts characteristically in kind, honest, compassionate, fair, and courageous ways; that is, in ways that reflect the type of person, the type of nurse, that Belanna is.

That we can make such judgements indicates that we acknowledge the idea of character, which lends weight to the idea of virtue ethics, because in virtue ethics character guides conduct. In other words, virtue ethicists will want to say that right action follows right character. And it is this primacy of character that distinguishes virtue ethics from other approaches to ethics. In our case-study, Belanna seems to represent a nurse with the virtues insofar as her actions appear to stem from her character traits. She acts in kind ways because she is a kind person; she acts in honest ways because she is an honest person, and so on.

From the basic tenet of virtue ethics – that individuals generally act in ways consistent with their character traits – it follows that those who wish to act in virtuous ways should seek to become virtuous persons. In so doing the question 'what should I do?' becomes one that is asked less often because in many situations, just as Belanna exemplifies, what a person should do is what they characteristically would do. But perhaps this language of virtues is off-putting or old-fashioned. Perhaps a change of language might be useful. So instead of a phrase such as 'virtue ethics requires those who wish to act in virtuous ways to become virtuous persons' we might say instead 'virtue ethics requires that those who wish to act for the good need to develop good traits of character'. The virtues of kindness, honesty, courage, and justice are perhaps better understood in modern vocabulary as character traits. And most people identify these as positive traits; traits that are admired and identified as good things in and of themselves; traits that are encouraged in society in general and in nursing (and other health care occupations) in particular (see for example, the NMC (2015) code for nurses).

Some Background Regarding the Idea of Virtue and the Idea of Virtue Ethics

The background information in this section is designed to help the reader gain an appreciation of the origins of the language of virtue.

Aristotle (1953 edn) held that being or doing good required cultivation of *aretê*. Aretê is translated most commonly as 'virtue' but sometimes as 'excellence' or 'moral virtue'. The Ancient Greeks understood aretê in a way that we might now describe as holistic: in other words, a person of aretê (a person of virtue or a person of excellence) would be a person with all the virtues or excellences necessary for a good life. Note that this idea of virtue is a composite – to be a person of virtue is to be a person with the appropriate set of virtues – possession of some but not other virtues would disqualify a person from aretê. Of course, the question then becomes what are the appropriate virtues – a question that has exercised successively, and among many others, Aristotle, Aquinas, and Austen as well as the disciplines of philosophy and psychology ever since. The idea of virtue ethics fell out of favour with the rise of Enlightenment thinking and the Industrial Revolution, following which the Victorians appropriated the word 'virtue' for ideas related to chastity, domesticity and religiousity. The rise of what we might now describe as modern ethical theory (that is, ethical theory that has evolved from the deontology associated with Kant and from the utilitarianism of Bentham and Mill) further relegated the idea of virtue ethics until the publication of ‘Modern Moral Philosophy’ (Anscombe 1958) which is credited as beginning a resurgence of interest in the idea of virtue ethics.

Most versions of virtue ethics draw from the Ancient Greek philosophy of Aristotle – and in this chapter I continue that tradition. (The reader should note that there are other, non-Aristotelian versions of virtue ethics.) One of the difficulties of working with ancient ideas lies in translation. It is not just that the ideas get lost in translation, it is more that many Ancient Greek terms often have no one direct equivalent in English. As noted above, aretê can be translated as ‘virtue’, ‘excellence’ or ‘moral virtue’. These different translations can represent significant changes in meaning, as can be seen above, where translating the idea of a person of aretê as ‘a person of virtue’ can be interpreted quite differently from the translation of ‘a person of excellence’. Hence the use of one rather than another translation can have significance for interpretation and understanding. There are two more ancient Greek terms that are important in Aristotelian or neo-Aristotelian virtue ethics: *eudaimonia* and *phronesis*. Eudaimonia is most often translated as ‘good life’, ‘happiness’, ‘human flourishing’, or just ‘flourishing’; phronesis as ‘practical rationality’ or ‘practical wisdom’. My preference is flourishing for eudaimonia and practical wisdom for phronesis.

Eudaimonia

Aristotle considered that all things (including persons) have a purpose and to pursue that purpose is to pursue the good appropriate for the thing that it is – this is the pursuit of eudaimonia. For Aristotle a good chair is a chair that performs as a chair should, so a chair that is unstable, or tends to unexpectedly eject its occupant, would not be a good chair. Similarly, a good horse is a horse that is able to excel in those things that makes a horse a horse and not, for example, a snake – thus eudaimonia for a horse without legs would be unlikely. The good for a human then lies in pursuit of that which is good for humans. For Aristotle it is the virtues that provide the platform for a good life for a person and it is in striving to cultivate the virtues that humans can excel. Note it is not the pursuit of an individual or a particular virtue but the pursuit of those virtues necessary for human flourishing.

Phronesis

The Ancient Greeks of this period, and thus Aristotle, did not separate individual from societal good, at least not in the way that we do in the 21st century. Thus Aristotle’s list of virtues reflects an Ancient Greek sociology – just as ours, as Alasdair MacIntyre (2007) argues, should reflect our own sociology. In other words a modern list of virtues should reflect the sociological norms of our time as well as those timeless virtues of honesty, courage, and justice. And for nursing, as I have argued elsewhere, at least some of these virtues can be identified in nursing codes (Sellman 1997, 2011).

Among Aristotle's list of virtues, phronesis (practical wisdom) is the uber-virtue, the one virtue to guide action in the form of knowing when to do the right thing. As Rosalind Hursthouse (1997) notes, there is much in virtue to guide action. The just person is inclined to act in just ways, the honest person in honest ways, and the courageous person in courageous ways. Yet while this tendency to act in ways consistent with cultivated virtues provides a starting point for good action and for pursuit of the good, there is a need for cultivation of the wisdom to know when and how to act in any one particular situation. This is the role of phronesis (practical wisdom) for without practical wisdom acting solely according to any one other virtue is likely to leave the actor at the mercy of her or his emotions. And while emotions are important in virtue ethics, they nevertheless require tempering with practical wisdom if acting for the good is the aim.

Virtue Ethics and Nursing

So what is it that virtue ethics can offer nursing? One common criticism of deontology and utilitarianism (and also of principlism) is the tendency, at best, towards rule or principle following and, at worst, towards cold calculation. We saw the results of rule following without regard to fellow human feeling witnessed by Danielle early on in her pre-registration nursing programme. While supporters of modern moral theory recognise the desirability for actions that respond to the human condition in some way, neither deontology nor utilitarianism rely on that as a factor for the measure of the good. At a minimum, virtue ethics can provide that aspect of humanity seemingly absent from extreme forms of deontology and utilitarianism; and better still, and following Hursthouse (1997), virtue ethics can enhance the terms of ethical debate.

Hursthouse notes that ethical debates tend to be couched in terms that emerge from thinking influenced primarily by modern moral theory. For example, rights, duties, obligations, and so on represent the common language of the abortion debate. Such language, she notes, serves to allow for, even justify, behaviour that can be *"… cruel, or callous, or selfish, light-minded, self-righteous, stupid, inconsiderate, disloyal, dishonest …"* (Hursthouse 1997, p. 235). She argues that human relationships do not rely on, and tend to be undermined by, individuals *"… constantly insisting on their rights …"* (ibid) and that any ethical theory that encourages such ways of thinking thereby permitting insensitivity towards others fails in some significant way. For Hursthouse virtue ethics can intercede and her use of the question: *"In having an abortion in these circumstances, would the agent be acting virtuously, or viciously, or neither?"* (ibid) refocuses the question of 'what should I do?' into a question of 'what action is a virtuous action?'; or 'what action is consistent with virtue?'

What Hursthouse seems to be alluding to here is the use of Aristotle's virtue of phronesis. The practical wisdom involved in deliberating about which actions are virtuous – which actions, that is, promote and contribute to human flourishing – is one of the things that distinguishes virtue ethics from modern moral theory. Actions that approximate fairness, honesty, kindness, compassion, sensitivity, and so on are clearly more consistent with ideas of human flourishing than ways of being that are, for example, dishonest, unfair, and unkind.

We can see how character traits that support the idea of human flourishing can be overturned if we return to Danielle's experience of seeing truth-telling being argued for as some sort of pre-eminent principle for guiding action. Telling the truth (being honest) is generally a good thing and is a general principle supported by most ethical theories. For a deontologist, truth-telling would seem to be a prima facie obligation regardless of the consequences – so from a deontological perspective, despite the distress caused to the patient, telling the truth looks like it was the right thing to do. For the utilitarian wanting to act in terms of a good outcome, telling the truth might have been considered the right thing to do if the belief was that an outcome in which the patient did not hold the false belief that her husband was alive, was the best outcome – but lying might also be considered as the right thing to do if the best outcome is considered to be that the wife does not become distressed. The virtue ethicist would not hold onto either the deontological or the utilitarian approach but would rather want to deliberate about right action based on which action would be the virtuous action. Consequences and obligations – particularly role obligations – would, of course, enter into that deliberation but so too would the exercise of practical wisdom. Recognising that being brutal with the truth will likely cause unnecessary distress, and might be regarded as callous or unkind, the virtue ethicist might devote more time to allowing the patient to come to understand what has happened to her husband: recognising also that being honest does not require being brutal with the truth but does require support and understanding. Danielle wonders how Belanna would have dealt with the situation. In asking this question, Danielle is asking the very question that virtue ethics considers appropriate in situations where what right action requires is not obvious, or in situations where, as here, actions supportive of the virtue of honesty might clash with actions supportive of the virtue of kindness.

Danielle admires Belanna and wants to try to become the type of nurse that Belanna is. This desire to be a particular type of nurse – a good nurse defined by pursuit of the virtues – is perhaps the first step in becoming that type of nurse and adopting a virtue ethics approach to practice. Danielle wants to develop her character so as to become a kind, honest, fair, courageous, and compassionate person. She may not find this easy at first, but if Aristotle is right in saying that by practicing being virtuous we can become virtuous, then Danielle will need to practice being, for example, kind, honest, fair, compassionate, and courageous. This will likely require vigilance in observing herself in action, honesty in reflecting on her actions, and humility in seeking feedback on her actions until such time as her actions become characteristically kind, honest, fair, compassionate, and courageous – and she may not always get it right. Nobody is perfect and our fictitious Belanna may well be an unattainable ideal. Yet in striving to become virtuous, having an idealised picture of the virtuous nurse may help to guide actions in those situations when seemingly different virtue actions might clash or when it is not clear what should be done in a particular set of circumstances. In asking 'how would Belanna act?' Danielle would be learning to develop the practical wisdom that is the hallmark of the virtuous agent;

and one day, perhaps, others may come to admire Danielle and seek first to imitate her ethical practice and then to become virtuous nurses themselves.

The Situationist Argument Against Character

One of the central ideas of virtue ethics is that human beings have, and can develop, a persistent character that guides, or even determines, action. Situationists question this assumption and point to empirical research to support their contention that character has less effect on behaviour than context does. They claim that we are prone to misattribute human behaviours as expressions of character. They posit that this continuing triumph of belief over evidence leaves us vulnerable to misunderstanding the nature of moral behaviour which in turn sustains a general belief that wrong doing is solely a matter of individual responsibility. The situationists point to, for example, Darley and Batson's 1973 Good Samaritan study (where a reduction in the amount of 'hurriness' rather than anything else was seen as the main factor predicting helping behaviour) and Zimbardo's 1971 Stanford prison experiment (where 'guards' and 'inmates' quickly fell into role specific and disturbingly harmful behaviours unrepresentative of their supposedly true and regular characters). Both studies powerfully illustrate the human tendency towards attribution failure as both provide strong indications that behaviour is determined as least as much, if not more, by situation rather than by individual character. These experiments, and many like them, show not bad people doing bad things but regular, every day, flawed human beings doings things that are less or more helpful or less or more harmful – determined, at least in part, by situation.

Of course, nurses are ordinary everyday people too, and are capable of doing harmful things as the reports into the events of Mid-Staffordshire illustrate (Francis 2010, 2013). Here we have reports of nurses acting in callous, unhelpful, inconsiderate, and seemingly indifferent ways towards patients. While most commenters are quick to apportion blame to individual nurses, Paley (2014) argues for a recognition of the effect situation can have on people's behaviour before rushing in to lay responsibility solely at the feet of individual nurses. If Paley and the situationists are right then the implication is that character may be less able to withstand circumstance than is generally imagined. If this is true then the implications for nursing and for the idea of a virtue ethics are profound.

Using the Situationist Critique to Enhance the Development of Character

However, even if the situationists are right this does not spell the end of character, or the end of a virtue ethics for nursing. On the contrary, an understanding of the corrosive effects of situation on character can be used to provide a platform from which a virtue ethics for nursing can be developed and from which individual nurses can cultivate appropriate virtue.

Situationists might argue that if we want people to act well (that is, in fair, honest, courageous, caring, and compassionate ways) then all that is needed is to provide situations that encourage good action and discourage harmful action. So if an increase in Darley and Batson's hurriness equates with a reduction in helping behaviour, then the remedy should be obvious; an increase in helping behaviour can be facilitated by a reduction of hurriness. In other words, if there is sufficient nursing staff to ensure that nurses are not constantly hurrying from one task to the next in the context of a seemingly never-ending and always-expanding set of things to get done before the end of shift, then they will be less hurried and more likely to stop to check that, for example, Mrs. Patel has fresh water to drink or that Mr. Rwani has the help he needs to get to the bathroom. In this scheme, it matters not if the individual healthcare workers are fair, honest, courageous, caring, or compassionate individuals – all that matters is that when those workers are less distracted, less busy, less hassled, they are more likely to take notice of, and help, fellow human beings in distress. And some might argue that the utility value in arranging situations such that it is easier for people to act in fair, honest, courageous, caring and compassionate ways is greater than that to be gained from attempts to inculcate those types of actions as dispositions in people while leaving them at the mercy of situations in which acting in ways consistent with those dispositions is the difficult option.

But there is a caveat needed here. If we arrange situations to encourage right action, then we are not encouraging virtuous action so much as automated action. There is nothing wrong with this if it is action for the good except that, outside of the carefully controlled situation, those who only know how to act within the controlled situation will struggle to know what are good rather than harmful actions. They will be acting in a purely behavioural response-to-stimuli manner which does nothing to cultivate virtue. So situation alone will not assist in developing the type of practical wisdom envisaged in a virtue ethics of an Aristotelian kind. More will be needed including a personal desire to become a better person – a better nurse – one who has developed the character traits that tend toward, for example, kind and compassionate actions as matter of inclination.

Conclusion

In this chapter I have offered a glimpse of what it might mean to be a good nurse in the sense understood in terms of virtue ethics. I have hinted at what a virtue ethics for nursing might look like and I have indicated how an individual nurse might begin to go about developing an appropriate set of virtues for nursing. Virtue ethics may not provide all the answers to nursing's pressing ethical problems, but as I have suggested in this chapter, neither do any of the other ethical approaches. I suppose from this it can be seen that I have pragmatic tendencies. At the very least, I believe that a case can be made for introducing virtue ethics into nursing as a way of offsetting the worst excesses of the mere rule following tendencies of modern ethical theory and its principle-based offspring.

Virtue ethics has its critics amongst which is its purported failure to provide action guidance. I hope that I have answered some part of that criticism by showing that a nurse who wishes to be kind, compassionate, caring, fair, honest, and so on in her or his work as a nurse can do so from the perspective of virtue ethics. One advantage I see in so doing is that the nurse with the virtues will tend to act in ways consistent with their character from inclination rather than against inclination. That is, the need to pretend to be kind, for example, will diminish over time as being kind becomes part of the person, part of the nurse. And this, it seems to me, provides a genuineness that may become absent when following rules and principles without due regard for the potential negative effects on patients' and others' flourishing.

I have noted too, that situationists argue that we are sometimes – perhaps even often – misled into thinking that people act from their character rather than from the forces of the situations they find themselves in. In my view this does not detract from the value of a virtue ethics for nursing. Rather, it indicates that the next step in virtue ethics is to arrange situations so that both right action is the easiest thing to do *and* the development of virtue in practitioners is encouraged. So often our best intentions are constrained, sometimes corrupted, by situational factors outside of our control. If this is true then it seems that what nurses need to focus on is to help create environments that are supportive rather than discouraging of the expression of the virtues in practice. But until this time individual nurses can use a virtue ethics of nursing to enhance ethical nursing practice in ways that are appropriate to their own particular spheres of influence. And to avoid the burden of thinking that each nurse must become the ideal virtuous nurse, remember that Belanna is a fiction used to illustrate an ideal, an ideal to which we might aspire rather than attain. After all, no one is perfect.

Key Learning Points/Salient Points for the Reader to Consider

1. The focus on character distinguishes virtue ethics from most other approaches to ethics
2. Acting in virtuous ways from inclination is consistent with calls for authenticity in nursing practice
3. Virtue ethics cannot answer all nursing's pressing ethical problems (but neither can any one other approach to ethics)
4. Virtue ethics is implied in much of the language used by nursing's regulatory and professional bodies
5. Virtue ethics requires individuals to develop their character for the good

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Care Ethics and Nursing Practice

5

Ann Gallagher

Abstract

Care ethics, also known as ethics of care, is one lens with which to view ethics as applied to nursing and care more generally. The beginning of this particular approach to ethics as applied to care is attributed to the work of Carol Gilligan and Nel Noddings in the early 1980s. Care ethics has evolved primarily in North America and Europe with different strands and input from philosophers and social scientists. This chapter traces the development of care ethics, summarises key elements and focuses on the work of two theorists – Joan Tronto and Chris Gastmans – and the implications for nursing ethics. A short case study from an ethics education research project suggests the value of applying insights from care ethics to everyday practice situations. The strengths and limitations of care ethics are discussed and it will be concluded that, whilst care ethics makes a valuable contribution to ethics as applied to care, other perspectives enhance this approach.

Keywords

Care ethics • Relationality • Vulnerability • Dependency • Dignity • Responsibility

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P.A. Scott (ed.), *Key Concepts and Issues in Nursing Ethics*,
DOI 10.1007/978-3-319-49250-6_5

Introduction

There has been scholarship on ethics as applied to care since the 1800s. Marsha Fowler (2016) points out that, from 1890 to the 1960s, approximately 50 texts were published on nursing ethics. Many of these were written by nurses but some were authored by social workers, priests or physicians. The topics within these texts are still relevant today, with discussions of confidentiality, truth-telling, the atmosphere of the hospital (what we would now refer to as ethical climate) and duties towards patients, the family, the doctor, towards the nurse herself, her friends, her hospital and school, and other nurses. Fowler argues that early nursing ethics:

> …effectively removes nursing's ethics from the realm of a "bedside ethics" alone to one that reaches into both the problems of society and the structure of society. These early requirements are the precursors to contemporary nurses' concern for health disparities. However, an examination of these historical requirements in social-ethical and social justice content, as well as the nursing ethics historical literature, indicates that nursing's perspectives on social justice do not align very well with the bioethical discourse on distributive justice and are far closer in spirit to the contemporary work by, Baier, Held, Kittay and colleagues […] Tronto and others who look closely at structural inequalities far more broadly than concerns for the costs and access to healthcare. (Fowler 2016 p. 11)

Baier, Held, Kittay and Tronto are but some of the leading theorists who have contributed to a particular approach to ethics as applied to care. This has become known as both 'care ethics' and 'ethics of care'. This one approach albeit with different varieties by different authors – primarily in Europe and the United States – emphasises the primacy of relationships of care. It is presented as remedying some of the deficits of bioethical approaches that focus on justice, principles and professional detachment. It is, however, but one lens that illuminates ethical aspects of nursing and care practices more broadly.

In this chapter, I will provide an overview of the evolution of care ethics and an explanation of the 'core' elements of care ethics. I will discuss the implications of the work of two care ethics theorists – Joan Tronto and Chris Gastmans – for nursing practice and consider the potential of care ethics to throw light on ethical aspects of a care situation. I will conclude by summarising some of the strengths and limitations of care ethics.

The Evolution of Care Ethics

The beginning of care ethics is generally attributed to the publication of Carol Gilligan's book I*n a Different Voice: Psychological Theory and Women's Development* in 1982. Whilst early writings from nurse scholars and from feminist and other philosophers (for example, Mayeroff 1971) had features of care ethics, it was Gilligan's work that is credited with initiating the particular approach which has become known as both 'care ethics' and 'ethics of care'. Around the same time, Nel Noddings published *Caring: A Feminine Approach to Ethics* (1984) which had much in common with the themes identified by Gilligan and later care ethicists. Michael Slote (2007 p. 10) has argued that it was Noddings, rather than Gilligan, who 'was the first person to attempt to spell out an ethics of care'. Nevertheless, it is Gilligan who is most often referred to as the originator and her research is most illuminating as background to the approach.

Gilligan's research challenged some of the findings of earlier work by American psychologist Lawrence Kohlberg and his perspective on stages of moral development. She reports findings from the presentation of a dilemma, devised by Kohlberg, to two 11 year old children, Jake and Amy. Gilligan (1982 p. 25–26) describes the situation as follows:

> The dilemma that these eleven-year-olds were asked to resolve was one of a series devised by Kohlberg to measure moral development in adolescence by presenting a conflict between moral norms and exploring the logic of its resolution. In this particular dilemma, a man named Heinz considers whether or not to steal a drug which he cannot afford in order to save the life of his wife. In the standard format of Kohlberg's interviewing procedure, the description of the dilemma itself – Heinz's predicament, the wife's disease, the druggist's refusal to lower his price – is followed by the question, "Should Heinz steal the drug?" The reasons for and against stealing are then explored through a series of questions that vary and extend the parameters of the dilemma in a way designed to reveal the underlying structure of moral thought.

Gilligan explains how Jake proceeds to respond logically as he sees the problem as "sort of like a math problem with humans" (p. 26). He constructs the problem as one of a conflict between 'the values of property and life' and concludes that Heinz should steal the drug. Jake was of a view that a judge "should give Heinz the lightest possible sentence". Amy, on the other hand, responded to the dilemma differently and appeared uncertain. She didn't think Heinz should steal the drug and wanted to explore other options, for example, borrowing the money for the drug or taking out a loan. She was mindful of the effect of a theft:

> If he stole the drug, he might save his wife then, but if he did, he might have to go to jail, and then his wife might get sicker again, and he couldn't get more of the drug, and it might not be good. So, they should really talk about it and find some other way to make the money (p. 28).

Gilligan points out that, unlike Jake, Amy does not see the dilemma as a maths problem but rather as 'a network of connection, a web of relationships that is sustained by a process of communication' (p. 32). Gilligan's analysis of the response highlights well the distinction between ethics as underpinned by logic and law and a 'different voice' of care:

> Instead, seeing a world comprised of relationships rather than of people standing alone, a world that coheres through human connection rather than through systems of rules, she finds the puzzle in the dilemma to lie in the failure of the druggist to respond to the wife. Saying "it is not right for someone to die when their life could be saved", she assumes that if the druggist were to see the consequences of his refusal to lower his price, he would realise that "he should give it to the wife and then have the husband pay back the money later". Thus she considers the solution to the dilemma to lie in making the wife's condition more salient to the druggist or, that failing, in appealing to others who are in a position to help (p. 29).

Many examples discussed in Gilligan's text illustrate different ways of thinking about ethics. She writes (p. 173):

> My research suggests that men and women may speak different languages that they assume are the same, using similar words to encode disparate experiences of self and social relationships […] may contain a propensity for systematic mistranslation, creating misunderstanding which impede communication and limit the potential for cooperation and care in relationships. At the same time, however, these languages articulate with one another in critical ways. Just as the language of responsibilities provides a weblike imagery of relationships to replace a hierarchical ordering that dissolves with the coming of equality, so the language of rights underlines the importance of including in the network of care not only the other but also the self.

We arrive at two distinct ethical perspectives set out in the conclusion to Gilligan's 1982 text (p. 174). It is worth quoting in full as this underpins much of the later development of care ethics:

> To understand how the tension between responsibilities and rights sustains the dialectic of human development is to see the integrity of two disparate modes of experience that are in the end connected. While an ethic of justice proceeds from the premise of equality – that everyone should be treated the same – an ethic of care rests on the premise of nonviolence – that no one should be hurt. In the representation of maturity, both perspectives converge in the realization that just as inequality adversely affects both partners in an unequal relationship, so too violence is destructive for everyone involved. This dialogue between fairness and care not only provides a better understanding of relations between the sexes but also gives rise to a more comprehensive portrayal of adult work and family relationships.

Gilligan's early research and conclusions regarding two different approaches to ethics and moral development continue to be very influential. However, limitations of her research have also been highlighted. Joan Tronto (1993), for example, points out that Gilligan's work does not challenge the boundary between private and public life and between justice and caring. An undesirable consequence is that relegating caring to private life it is considered to be outside the political realm and not considered as part of public life. Tronto argues that the work of Gilligan – and also that of Kohlberg – 'maintain the position of the relatively privileged' (p. 96) whereas valuing care should be considered as both a moral and a political process.

Theories strengthening the idea that the ethics of care is a defensible alternative to an ethics of justice – or should be combined – have been developed by philosophers and feminists such as Joan Tronto (1991 with Fisher, 1993, 2013), Virginia Held (1993, 2006), Eva Feder Kittay (1999, 2002) and Sara Ruddick (1989). In relation to nursing care specifically, ethicists such as Chris Gastmans, Per Norvedt and Helen Kohlen continue to develop this approach. It is not possible to do justice to the work of all of these care ethicists so I focus on two. Before discussing the contribution of Joan Tronto and Chris Gastmans – with reference to an aspect of Kittay's work – elements of care ethics will be discussed.

The Core of Care Ethics

There is much diversity in care ethics and many rich perspectives continue to be developed. It is difficult to determine exactly what is agreed as constituting the approach. Political theorist, Stephanie Collins (2015), helpfully sets out a care 'slogan' and four claims. The slogan is 'dependency relationships generate responsibilities'. The four claims which, Collins argues, 'capture what is distinctive about care ethics' are detailed below with some suggestions as to how they relate to care practices and to other approaches to applied ethics:

Claim 1 'Ethical theory should positively endorse deliberation involving sympathy and direct attendance to concrete particulars' – This claim suggests a requirement fulfilled by most ethical perspectives with potential application to care practices. It seems unimaginable that an ethical theory could be worthy of consideration that accommodated unsympathetic and inattentiveness to concrete particulars. Ethical approaches that accommodate human sympathy and an emotional component of the moral life, such as virtue ethics, will also satisfy this claim.

Claim 2 'To the extent that they have value to the individuals involved, relationships ought to be (a) treated as moral paradigms,[1] (b) valued, preserved or promoted (as appropriate to the circumstance at hand) and (c) acknowledged as giving rise to weighty duties'[2] – The relational focus of care ethics is different to most other ethical approaches. It is not, for example, a focus of the four principles approach or utilitarianism. However, it is a key feature of 'relational ethics' (Pollard 2015; Austin 2006).

Claim 3 'Care ethics sometimes call for agents to have caring attitudes, that is, attitudes that: (i) have as their object something that has interests, or something that might affect something that has interests; and that (ii) are a positive response (e.g. promoting, respecting, revering) to those interests; and that (iii) lead the agent's affects, desires, decisions, attention, and so on to be influenced by how the agent believes things are going with the interest-bearer'. – Care ethics in the context of care practices always calls for agents to have caring attitudes that focus on a positive response to the interests of others. This is an element that is, arguably, shared with virtue ethics[3] whereby the virtue of care is a moral disposition that contributes to the flourishing of the care recipient and the care giver (Banks and Gallagher 2009).

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[1] By 'moral paradigm' Collins (2015) means that caring relationships should be extended beyond relatives, that is, we should adopt the same kind of attitude to non-relatives (see page 35).

[2] For a discussion of the nurse-patient relationship as a lens to view the moral/ethical domain of nursing practice please see Chap. 1.

[3] Please see Chap. 4 for an introduction to virtue ethics.

Claim 4 'Care ethics calls for agents to perform actions (i) that are performed under the (perhaps tacit) intention of fulfilling (or going some way to fulfilling) interest/s that the agent perceives some moral person (the recipient) to have; (ii) where the strength of the demand is a complex function of the value of the intention, the likelihood that the actions will fulfil the interest, and the extent to which the interest is appropriately described as 'a need.' – Responses to the needs of others, particularly those who are considered most vulnerable and dependent, is a central feature of care ethics and has to be, arguably, the focus of any ethical perspective applied to care. Approaches to ethics that can be described as teleological, with a *telos* or end in mind, have some similarities although the nature of the end aspired to will differ. In care ethics, Collins refers to interests and need. In utilitarianism, the end aspired to is happiness or the good of the majority.[4] In virtue ethics, the end aspired to is human flourishing (Banks and Gallagher 2009).

Collins goes on to argue that, whilst the four claims capture the distinctiveness of care ethics, they require an overall unifying principle. This is described as 'the Dependency Principle' which has four components: '*there is an important interest that is unfulfilled; an agent is sufficiently capable of fulfilling that interest; the agent's most efficacious measure is not too costly; and […] the agent's fulfilling the interest would be the least costly of any agent's doing so'* (p. 97).

The four claims as outlined by Collins present the core features of, and ethical justification for, care ethics. They can also be more fully fleshed out when considered in relation to the Dependency Principle (See Collins 2015 Chap. 8). However, they are somewhat elusive as normative prescriptions for everyday care practice and are not so clearly distinct from other approaches to ethics as applied to care. There are clearly similarities with virtue ethics and relational ethics, for example, and differences with autonomy-focused approaches to ethics. What is particularly valuable about care ethics is the recognition that care is crucially important and that any analysis of care requires both ethical and political insights. One of the most important care ethicists, Joan Tronto, brings her moral and political expertise to bear on care sharing insights and implications for individuals, organisations and global communities.

Perspectives on Care Ethics: Joan Tronto

The year 2013 marked the 20th anniversary of Joan Tronto's 1993 text *Moral Boundaries.* Many of the features of Tronto's version of care ethics have direct and obvious implications for nursing and other care practices and have been discussed elsewhere, for example, in a text marking the 20th anniversary of *Moral Boundaries* (Gallagher 2014). Three features of Tronto's work are discussed here: her description of the phases of care and the ethical attitudes that accompany them; her

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[4] For an introduction to Utilitarianism please see Chap. 3.

discussion of the role of care and caregivers; and an explanation for unethical practice. First, lets look at the definition of "care" proposed by Tronto and Fisher (1991 p. 40):

> On the most general level, we suggest that caring be viewed as a species activity that includes everything that we do to maintain, continue and repair our "world" so that we can live in it as well as possible. That world includes our bodies, ourselves, and our environment, all of which we seek to interweave in a complex, life-sustaining web.

Tronto (1993) points out that their definition intentionally highlights that caring includes caring for objects that are not human; that it is not restricted to individuals or 'dyads' but rather should be thought of as part of wider social networks; that it is 'defined culturally'; and that it is ongoing. Tronto (1993 Chap. 4) outlines the four phases of care and the ethical attitude that accompanies each (Table 5.1).

People 'care about' many issues, individuals and artefacts, however, they may go no further than notice a need for care. 'Taking care of' requires more of an investment. It requires taking responsibility to improve the situation of another. This could involve making a donation to a charity or, more personally, making arrangements for a loved one to receive care from a domiciliary, residential or day care facility. The third phase – 'care-giving' – requires a direct engagement with care. It requires competence to deliver care adequately. The fourth phase of 'care-receiving' involves the responsiveness of those receiving care where, that is, they are able to provide a response. Those who are unconscious, who are psychotic, too young or who have severe dementia may be unable to appreciate the experience of receiving care or to recognise the difference care makes.

Regarding the role of care and caregivers, Tronto (1993 p. 117) clearly articulates the importance and devaluation of care in society. Her view clearly also has a political dimension:

Table 5.1 Tronto's dimensions or phases of care

Dimensions/phases of care	Ethical attitude
Caring about – This involves the 'recognition that care is necessary' and includes concern, worry about someone or something. This could include making a donation to a charity where a need has been recognised.	**Attentiveness** – noticing need for care
Taking care of – This next step of the caring process involves taking responsibility for tasks relating to the provision of care and looking after someone. This could include arranging care for a child or elderly relative.	**Responsibility** – to improve the situation of someone
Care-giving – The 'direct meeting of care needs' involves delivering care to someone and includes the activities of nurses and other care-givers.	**Competence –** having the knowledge, skills and values necessary to meet the goals of care
Care-receiving – This final phase of care focuses on the care-recipient, on the difference care makes and on their response to care and their feedback.	**Responsiveness –** saying 'thank you', responding positively to care delivery

> Care is difficult work, but it is the work that sustains life […] The fact that care-givers can see an essential truth about the value of care, though, does not negate the fact that care is reduced to a lesser importance in society as a whole. When we look at the distribution of such rewards as money and prestige, it is clear that we value much else before care.
>
> To recognise the value of care calls into question the structure of values in our society. Care is not a parochial concern of women, a type of secondary moral question, or the work of the least well off in society. Care is a central concern of human life. It is time that we began to change our political and social institutions to reflect this truth (p. 179).

Despite a recognition of the importance of care, it is sometimes the case that there are care deficits where care recipients are neglected, humiliated and abused (Francis 2013; Bubb 2014). Some of these violations may arise, according to Tronto, when there are inadequate resources or when the caregivers' own needs are unmet. They may come to resent the care-recipients they are charged with delivering care to. Tronto writes (Tronto 1993 p. 143):

> […] care-givers are often enraged about their own unmet needs. If they are unable to recognise this rage, care-givers are likely to vent their anger on those for whom they care. Perhaps some rage is appropriate, but when it subverts the process of care itself, then it poses a serious moral problem.

The theme of care deficits and mistreatment is also examined by Eva Feder Kittay (Kittay 2002), most particularly in relation to institutional care for those with learning disabilities. She argues that where caregivers are exploited they may become 'victimisers' as well as victims. 'In such a society', she writes, 'care will be minimal, and callous caretakers will be inevitable' (p. 269). She goes on to say:

> […] abusive behaviour by those who are charged with providing care is facilitated not only by the social devaluation of persons with mental disabilities, but also by the devaluation of the caregivers themselves. If we want to remove the prejudice and lack of understanding that blights the lives of people with mental retardation we can begin by treating their caregivers as if their work mattered (because it does) and as if they mattered (because they do). To do this we need to provide caregivers with conditions that allow them to do their work well and receive just compensation […] compensation that matches the intensity of their labour, and encouragement in their sympathetic and empathic responses to their charges (p. 270).

Caring for the caregivers is an understandable and important priority. So too, is understanding the reasons for unethical behaviour in care practices. This is particularly pressing in the light of recent high profile care scandals. What is most helpful from the perspectives of Tronto and Kittay is the extension of explanations beyond individual blame to societal and political explanations. Tronto's (2013) recent work has developed what Barnes et al. (2015 p. 4) refer to as 'the political character of feminist virtue ethics'. The next section discusses the perspective of a European philosopher and theologian who is well known for his work in nursing ethics.

Perspectives on Care Ethics: Chris Gastmans

Chris Gastmans has been actively involved in researching philosophical and empirical aspects of ethics as applied to care for over two decades. His research and scholarship has been influential in interpreting elements of care ethics for everyday nursing practice (see, for example, Gastmans et al. 1998, Gastmans 1999, Vanlaere and Gastmans 2011, and Gastmans 2013). Three of his papers will be the focus of this section: collaborative work with de Casterlé and Schotsmans on nursing as a moral practice and the concepts of 'good care' (Gastmans et al. 1998); and more recent writing on 'dignity-enhancing care' (Gastmans 2013).

In the 1998 article, Gastmans, de Casterlé and Schotsmans develop a model for 'nursing considered as a moral practice' with three main components: the caring relationship (a condition of nursing practice); caring behaviour ('integration of virtue and expert activity) and 'good care' described as 'the final goal of nursing practice'. Regarding the caring relationship, Gastmans et al. (1998) discuss the perspectives of the nurse as care giver and the care recipient. They write:

> Caring generally can be considered as a specific way of relating oneself to the other in a relational context, with attention given to the maintenance and the development of the other (patient) and oneself (nurse) (p. 49).

Gastmans and his co-authors emphasise the *otherness* of the patient and the importance of recognising the uniqueness and value of the patient with a view to helping him/her to grow and to maximise 'his or her own life development' (p. 49). An important feature of this discussion is the focus on self-care. It is argued that nurses need to care for themselves if they are to care well for patients. Building on the work of Tronto (1993) and Noddings (1984), they argue that care receivers play an important part in the way care is interpreted and judged in relation to their care needs. Caring behaviour, according to Gastmans et al. (1998), involves the integration of virtue (altruistic virtue of care with cognitive and affective-motivational features) and expert activity (including technical competencies).

Nursing is defined as:

> […] a relation-based practice that is directed to providing good care to (usually sick) human beings (p. 52).

For Gastmans and his co-authors, 'good care' is the 'goal and foundation of nursing practice'. To better understand and illuminate what is meant by 'good care', they draw on European philosophical perspectives on 'being human' (p. 59). Their approach elaborates on six dimensions of the patient: the physical; the relational; the social; the psychological; the moral; and the spiritual. Understanding the concept of 'good care' is also described as requiring engagement with insights from psychology, philosophy, sociology, nursing and medicine. Overall, then, nursing is described as a practice with three components: the caring relationship; the integration of virtue and expert activity; and 'good care as the goal of nursing practice'.

Good care involves engagement with six dimensions. Gastmans and colleagues argue that:

> Care is more than simply the sum of the various aspects that can be differentiated in the concept. A comprehensive description of good care involves a number of dimensions and is not simply the juxtaposition of detached properties and domains of thought. Constructing an ethical concept such as good care is impossible without drawing on data from the diverse human sciences such as philosophy, psychology, sociology, nursing science and medicine. But from an ethical point of view, the various components cannot be considered separately from each other – they influence and invoke each other. (Gastmans et al. 1998 p. 66).

Another version of care ethics, proposed by Chris Gastmans, is described as 'dignity-enhancing care' (Gastmans 2013). The three core ideas or concepts are proposed as central: dignity, care and vulnerability. Gastmans writes that much scholarship in medical ethics has focused on the four principles approach – respect for autonomy, beneficence, non-maleficence and justice. However, this approach (principlism) is concerned with questions such as 'what is to be done?' or 'what act or decision is to be taken? […] Gastmans argues that care does not involve isolated decisions but rather that those 'caring for patients go through a whole process of care'. He argues that we need to engage with three components: lived experience (vulnerability); interpretative dialogue (care process); and normative standard (dignity). These three components are aspects of an 'ethical framework to inspire our reflection on the ethical essence of nursing' (p. 146). Further interrogation is required in relation to each of these concepts and some of this will be developed in the next section.

A Practice Situation – Case Study

The following is an example from focus group data relating to a care situation from a research project which evaluated three different approaches to ethics education for residential care givers (Gallagher et al. 2016, Gallagher and Cox 2015). The residential care-givers assumed the role of care recipients and care was delivered by student nurses. The context was a meal time where a care-recipient attempted to eat a slice of cheesecake with the use of one hand:

> I just kept picking up that whole entire thing where it was quite sticky and really gooey and it's cheesecake, I just want to plough in. And I just couldn't get anything. And before I'd realised it, her hand had just come across the table, she hadn't even looked at me, and she was just like that, and she just carried on talking. And just from that simple movement I was able to feed myself my cheesecake. And that was brilliant because there was no 'Oh do you want any help with that?' it was just a gentle little … yeah, to make it blatant to everyone … it was just a little slide of a hand, place the fingers on it and just carried on talking … nobody … I didn't actually even notice that she'd done it until I'd actually finished. [RIPE project Focus group 5]

The student nurse care-giver shared her view of the same situation:

> I didn't want to take away her ability to eat the cheesecake, cos I could have gone 'Give me the cheesecake, I'll help you' or you know 'Let me spoon it …' I wanted to enable [care recipient] to eat her cheesecake herself, you know she had the ability to do it with her good hand. And

> I thought it would empower you more to eat the cheesecake herself and just have this ever so slight intervention. [Focus group 5]

These two extracts provide an example of a care giver assessing what the care recipient needed and acting in a way that she thought empowering. The care giver acted spontaneously and non-verbally in response to a perceived need. From a care ethics point of view, it could be argued that the student care-giver was sensitive to the vulnerability of the care recipient and to the potential for indignity. As the care recipient suggested, her deficit was not made public and attention was not drawn to it which could lead to a loss of dignity. In terms of the relevance of other care ethics concepts and dimensions, we might draw on Tronto's four phases of care, focusing on care giving and care receiving and the associated 'attitudes' of competence and responsiveness.

In terms of the six dimensions of good care outlined by Gastmans et al. (1998), the physical, relational, and moral appear most pertinent. They point out that the provision of care to maintain and improve the patient's physical condition is an essential part of good care. They discuss the serving of meals explicitly:

> Having a meal is more than the functional consumption of food for purely physical ends. The serving of meals in a health care institution is, in our opinion, a very important case in point that must be elevated above its merely nutritional function in order to maintain its human character […]. By approaching the patient's body in a prudent and respectful way, nurses can bear witness to their own striving toward care and human dignity (p. 60).

The example also relates to the relational dimension where space needs to be made for the development of a caring relationship. As meals are taken, as in this case in a social context, there needs to be sensitivity as to how the intervention will be perceived by other care recipients. A subtle, non-verbal intervention appears attuned to the needs of the care recipient. As this example comes from a simulated care ethics education intervention, there may be a question of authenticity of the experience. However, both care recipient and care giver were able to articulate the impact of the example as 'good care'. Concepts, then, such as vulnerability, dignity, care, competence, relationality, and responsiveness appear to be applicable to this simulated practice example and resonate strongly with the care ethics literature. If this were to be considered through another ethical lens, different concepts may be considered, for example, the four principles' approach (Beauchamp and Childress 2013). The focus would then perhaps have been on respect for autonomy, weighing benefits with potential harms and justice. If we were to draw on a virtue ethics approach, virtues in addition to care could be considered such as prudence, respectfulness and kindness.

Care Ethics and Nursing Ethics: Strengths and Limitations

The strengths of care ethics in relation to care practices seem obvious as it addresses fundamental ethical aspects of care. It is difficult to imagine how ethical discourse relating to care could proceed without reference to vulnerability, dignity, receptivity and the concept and value of care itself. However, challenging aspects of the approach have also been discussed. Maureen Sander-Staudt (n.d.), for example, suggests six potential criticisms of care ethics: that it is a 'slave morality'; that it is empirically flawed; that it is 'theoretically indistinct'; that it is parochial; that it is essentialist; and that it is ambiguous.

Care ethics as a 'slave morality' – Sander-Staudt advises that the term 'slave morality' is attributed to the philosopher Nietzsche who argued that people who are oppressed tend to 'develop moral theories that reaffirm subservient traits as virtues'. The view that care ethics supports the oppression of women is deserving of further attention. As Sander-Staudt states: 'This objection further implies that the voice of care may not be an authentic or empowering expression, but a product of false consciousness that equates moral maturity with self-sacrifice and self-effacement.'

Care ethics as empirically flawed – This critique focuses on the robustness of Gilligan's research. It is alleged that her sample is too narrow and homogenous.

Care ethics as theoretically indistinct – It has been argued that care ethics is not clearly distinct from other ethical approaches and shares many of the same values, for example, equality, autonomy and justice. It has particular similarities with virtue ethics particularly when care is construed as a virtue.

Care ethics as parochial – This criticism stems particularly from claims by Nel Noddings that care obligations were primarily to those who are close rather than to distant people. There is a concern that 'without a broader sense of justice, care ethics may allow for cronyism and favouritism toward one's family and friends.

Care ethics as essentialist – There is criticism of a tendency within care ethics to focus on a 'dyadic model of a (care-giving) mother and a (care-receiving) child, on the grounds that it overly romanticizes motherhood and does not adequately represent the vast experiences of individuals'. Differences within gender groups tend to be overlooked and the complexity of sexual identity and sexual orientation downplayed. Black and lesbian women, for example, are likely to be different to white heterosexual women. Recent discussions of the relationship between care ethics and 'intersectionality' (Ward 2015) engages constructively with this criticism.

Care ethics as ambiguous – The accusation of ambiguity stems from the view that care ethics does not provide concrete guidance on what to do. In response to this criticism, Sander-Staudt points to a range of principles that are central to care ethics relating to, for example, the origin and fundamental need for care, the nature of care relations and the 'scope of care distribution'.

Conclusion

Care ethics or ethics of care is an approach to ethics in care that continues to evolve with contributions from philosophers and social scientists. Although some theorists have chosen to focus on the gendered aspect of care ethics, most do not. Increasingly there is also a recognition that embracing care does not exclude a commitment to justice and that care needs to be considered in the public as well as in the private domains, hence an emphasis on both the moral and political underpinnings of care. The four phases of care and accompanying attitudes identified by Joan Tronto and her discussion of the role of care givers and explanations for unethical practice (along with Kittay 2002) provide helpful insights. Chris Gastmans' discussion of 'good care' and 'dignity-enhancing care' can also be applied to everyday care situations. The six criticisms of care ethics discussed by Sander-Staudt (undated) need to be kept under review as the approach evolves.

As care ethics is currently an umbrella for a disparate range of theoretical accounts, it seems unlikely that it will replace well-established approaches such as the four principles' approach, deontology, utilitarianism, rights-based ethics or virtue ethics. However, it is hoped that this chapter illustrates the richness of the concepts and elements that contribute to an understanding of 'good care'.

Key Learning Points

- There has been scholarship relating to ethics and care, most particularly nursing, since the mid-1800s.
- The beginning of 'care ethics' – also known as 'ethics of care' – is attributed to the work of Carol Gilligan and Nel Noddings in the early 1980s.
- The scholarship of Joan Tronto and Chris Gastmans has been highlighted as providing helpful insights that illuminate ethical aspects of everyday care.
- Six criticism of care ethics, as presented by Sander-Staudt (undated), should be reflected on and discussed by all who consider the potential of care ethics as an effective applied ethics for everyday care.
- At this point, care ethics should not be considered as an alternative to other approaches to applied ethics in care but rather be seen as a rich approach that challenges more individualistic, gendered and apolitical approaches.
- Care ethics continues to evolve and is likely to continue to contribute to our understanding of ethical and political dimensions of good care over the longer term.

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The Concept of Person

6

Alan J. Kearns

Abstract
This chapter provides an overview of the concept of person and its significance for moral decision-making. The concept of person can be employed in discussions about difficult ethical issues, particularly those that arise at the beginning and end of life. Although philosophical reflections vary, self-consciousness, rationality and moral agency tend to be the main characteristics that define a person in contemporary discourse. Working with an explicit concept of person may be helpful when examining some of the ethical issues in nursing practice and healthcare. However, some of the resulting implications of using a concept of person may be counter-intuitive to nursing's duty to care, especially for those who are most vulnerable.

Keywords
Human Being • Person • Potentiality • Moral agency • Rationality • Self-consciousness • Speciesism

Introduction

When you are working as a nurse and are administering an injection or checking temperature, measuring blood pressure or fixing an I.V. fluid line, changing a wound dressing or feeding a patient, do you ever wonder whether the individual in front of you – whether it be an adult, a child, or a new born baby – is a person? Is there a difference between considering someone to be a person and considering them to be only a human being? These may seem strange questions at first. However it is part

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P.A. Scott (ed.), *Key Concepts and Issues in Nursing Ethics*,
DOI 10.1007/978-3-319-49250-6_6

of the very role of ethics to critically reflect, in a systematic manner, on concepts that we use daily, including those we use in nursing. The concept of human being refers to those entities who belong to the *Homo sapiens* species, whereas the concept of person is a special category that usually has a normative function, i.e. it generally implies that if an individual is a person, they should be treated with respect, their dignity should be acknowledged and their rights upheld.[1]

But what is a 'person'? When we first think about what a person is, we may envisage that a person is someone who has a sense of who they are within a context of a past, present and future. A person is someone who has an ability for thinking and communicating, who can direct their life through choices, preferences and values, who is able to evaluate actions from the perspective of right and wrong, duty and obligation, virtue and vice and who can make moral choices and take moral actions. From all of this, it can be said that there is something particularly special about persons.

However, when we begin to probe even deeper into the concept of person we come up against important perennial philosophical questions: What constitutes a person? What are the attributes and traits that are needed to be a person? Is a person a kind of entity that is rational? To whom does the concept of person apply? Is a human being *de facto* a person? Are there some human beings who are not persons? Are there some animals who are persons? How we come to answer such questions can have significant moral implications.

The task of examining the descriptive meaning and normative significance of the concept of person can be done in different ways to advance strong philosophical positions and ethical outcomes.[2] However, the goal of this chapter is not to advocate or endorse a particular view of what a person is but rather to provide an overview of the main defining elements of some of the contemporary views on the concept of person and their significance for moral decision-making in nursing and healthcare.[3]

The Importance of the Concept of Person

Generally, the development of important philosophical concepts gradually arises in response to deep searching questions about human existence. The goal of the originating discussions[4] about the concept of person were deemed to be essential and

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[1] See section on the importance of the concept of person below, pp. 70–73.

[2] Some of various concepts of person outlined in this chapter do not reflect the views of this author. This chapter is primarily intended to provide a survey of some of the main views on the concept of person.

[3] There is an enormous range of literature in the field of philosophy, theology and bioethics that examines this topic as well as a variety of concepts of person put forward by notable scholars which cannot be addressed within the limits of this chapter. This is such a vast topic with slightly varied accounts. Considerations here will be limited to the most pertinent philosophers and an overview of their ideas in this debate, rather than a detailed analysis of the complexity of their positions.

[4] A very good historical overview of the evolution of the concept of person can be found in Clark (1992).

critical for many reasons. For example, in the third and fourth centuries CE[5] the concept of person was used as a way of addressing some perplexing issues regarding the Christian religion's understanding of God as Trinity and Jesus Christ as both God and man (Zagzebski 2001 p. 404). The philosopher Boethius in the sixth century CE is accredited with providing the first philosophical definition for the term person (Clark 1992 p. 14). When he philosophically defines person as *"the individual substance of a rational nature"* (cited in Teichman 1985 p. 175), it is however still for religious reasons as it takes place in the context of a discussion on the understanding of the Trinity and the Incarnation of Jesus Christ (Clark 1992 p. 14).

Today the concept of person is not only of interest for such theological matters but can be used to justify certain positions on acute ethical issues that can affect nursing practice and health care. The great advancements in medicine and technology have led to many positive possibilities at our disposal regarding the efficacy of nursing and health care to respond to sickness and disease. Continual breakthroughs made by medical research have given the concept of person a renewed emphasis and the impetus to develop a concept of person that aims to speak to a contemporary world has gained momentum. To take a couple of examples: How do we frame a concept of person that is useful and applicable for the debates on highly charged issues such as developments in research at the beginning of life and the fact that we can generate life in a dish? If an embryo is deemed not to be a person with moral status and rights, then knowing this may make decisions to either research on it or to discard surplus embryos in the IVF (in vitro fertilisation) process much clearer, as there may be less of – or no – moral issue. In addition, the abortion debate often provides a context to examine issues regarding when life begins, how the early stages of life should be evaluated and whether we have personal life at the early stages of life. Abortion debates can often steer the conversation on the concept of person. For example, if an embryo is deemed not to be a person, then the value that is attributed to this stage of development in life may not be the same as that attributed to a child or an adult person. On the other hand, if an embryo is deemed to be a person, then clearly decisions to either research on it or to discard it would be more difficult. A concept of person could be used to question the legitimacy of scientific research on embryos, some reproductive technologies practices, and abortion.[6]

If premature babies and very young infants are deemed not to be persons, then we may have no particular moral obligations to them, or our moral obligations to them may be reduced, and they may have no or only reduced moral rights. Knowing this may bring clarity to some ethical issues regarding their care, especially if they are very sick with no prospect of recovery. On the other side, if premature babies and very young infants are deemed to be persons, then they would have the same moral rights and claims as adult persons.

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[5] Common Era. This is a general term to refer to the present calendar time. CE is sometimes used instead of AD, i.e. *Anno Domini*.

[6] Please see Chap. 9 of this book for further discussion of ethical issues at the beginning of life.

End of life issues emerging from brain stem death criteria, artificial prolongation of life by ventilation, artificial nutrition and hydration, and persistent vegetative states (PVS), for example, also focus the attention on when personal life concludes.[7] In some of these cases, if the individual is deemed to be no longer a person, then knowing this may make some end of life decisions much clearer as there would be less of a – or no – moral issue (although we would still want to treat such individuals in these situations well by virtue of what they were). On the other hand, if the individual is still deemed to be a person, then we would have particular moral obligations to them arising from their moral rights and claims.

Such ethical issues can be examined from many lenses such as principlism, and other modern and contemporary ethical theories.[8] The concept of person can also be employed in these discussions to bring clarity to nurses and other healthcare professionals and to enable them to take steps towards resolving ethical issues generated by beginning and end of life situations.

Distinguishing Persons from Human Beings

Ordinary conversation would reveal that we normally do not make a distinction between a person and a human being or consider that there may be a distinction to be made in the first place. In day to day discussions, novels, newspapers and other publications, both terms are often used interchangeably. The *Oxford Dictionary & Thesaurus* explains that the origin of the term ‘person’ is derived from the Latin word *persona*, which meant a mask worn by an actor (2007 p. 765). However, in philosophical circles a distinction between person and human being is generally recognised (Kadlac 2010 p. 421). The term human being refers to entities who belong to the *Homo sapiens* species whereas the concept of person is a philosophical, ethical and legal concept.[9] Therefore, for some, the categories of human being and person are not morally equivalent. To accept that there is a distinction between human being and person can lead to a number of possible positions:

Firstly, the concept of person cannot be reduced or restricted to any particular species. In principle, human beings may not be the only species that can be persons. Therefore, in theory, any entity that reveals certain properties and characteristics may be a person. Such entities could include particular animals or other life forms – should they exist – in our vast universe. By not anchoring the concept of person in any particular species we cannot be charged with the accusation of speciesism, i.e. to give preference to members of our own species because they are members of our own species (Singer 1993 p. 88). If species membership was the fundamental

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[7] Please see Chap. 10 of this book for further discussion of ethical issues at the end of life.

[8] The four principles of bioethics, as set out by Beauchamp and Childress (2013), would be an example of principlism. Deontology and Utilitarianism are examples of modern ethical theories (see Chaps. 2 and 3 of this book). Care ethics is an example of a contemporary ethical theory (see Chap. 5 of this book).

[9] Corporations can be considered to be ‘persons’ under law.

requirement for personhood, then it would act as a kind of firewall against other entities obtaining personhood status. By cutting lose the concept of person from human being, the potential to include other entities from other species as persons – and therefore recognise their dignity as persons – is potentially increased. Any committed supporter of animal rights, for example, would find this distinction between human being and person useful as some animals may be – or indeed are – persons and should be treated as such. This could have significant implications for using animals in research or as food items, and for the issue of captivity or the use of animals for manual work purposes.

Secondly, the distinction between human being and person may lead to the view that an individual human being, depending on their stage of development and health, may not yet be a person or may have ceased to be a person.[10] Not only can individuals become persons, they can cease to be persons and yet still go on living. In other words, they are biologically, but not personally, alive. There may also be human beings who may never become persons. If there are human beings who may not be – or indeed are not – persons, this could have important implications for their use in medical research and/or their nursing care and healthcare treatment. This does not necessarily imply that we treat 'human non-persons' badly but we may not be obliged to treat them in the same way as persons. In such situations we could refer to a distinction between welfare and autonomous rights (and by extension, duties).[11] In other words, we may want to claim that in some situations 'human non-persons' may possess welfare rights but not autonomous rights. Briefly, as Harris (2002 p. 95) explains, welfare rights are concerned about being taken care of, or being provided for, whereas autonomous rights are concerned about rights regarding making personal choices and decisions. Welfare rights are granted and protected by a state, for example a particular standard of living (UN 1948 art. 25), and can be given to those individuals who are not autonomous. Whereas autonomous rights belong to those who can make autonomous choices and decisions. Welfare rights tend to be 'positive' (e.g. the state providing a welfare benefit as in case of a long-term illness that prevents someone from the possibility of employment) rather than 'negative' (e.g. not being prohibited from autonomously deciding on ourgoals in life) (Griffin 2000 p. 28). Those who are deemed to be 'human non-persons' would not be autonomous agents with rights and duties, however they could be granted welfare rights. For example, in research ethics, when vulnerable populations such as very young children are needed to participate in medical research, there is heightened awareness of the need to ensure that they are taken care of, that they are not exploited and that their rights granted to them in law are upheld. Yet at the same time, it is generally recognised that very young children are not autonomous and therefore cannot exercise their right to give informed consent. In such situations generally valid consent can only be granted by a parent or a legal guardian.[12]

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[10] This is further discussed below with the hypothetical case study of John.

[11] See Chap. 7 of this book for a fuller discussion of autonomy.

[12] See Chap. 14 for a discussion of ethical principles relevant in the context of research.

Although philosophical reactions to the concept of person vary, self-consciousness, rationality and moral agency tend to be the main characteristic in contemporary discourse. While this broad view on the concept of person is generally shared, it has certainly been open to challenge.

Concepts of Person

The origination of the emphasis on self-consciousness, rationality and moral agency, can be traced back to the philosophers John Locke and Immanuel Kant.[13] Locke emphasises self-consciousness and capacity for thinking, whereas Kant emphasises an agency that is rational, autonomous and has the ability to act on moral principles, as defining personhood (Gillon 1985 p. 1735 ; Altman 2014 p. 250).[14]

Locke deals with the issue of identity and personhood in *An Essay Concerning Human Understanding*. For Locke (1964 p. 211/§9), the concept of person refers to *"… a thinking intelligent being, that has reason and reflection, and can consider itself as itself, the same thinking thing, in different times and places; which it does only by that consciousness which is inseparable from thinking…"*. The starting point of personal identity entails identity of consciousness rather than of substance (Locke 1964 pp. 211–213/§9–10). Self-consciousness and thinking lie at the heart of personhood. The concept of person is *"… a forensic term, appropriating actions and their merit, and so belongs only to intelligent agents, capable of a law, and happiness and misery"* (Locke 1964 p. 220/§26).

Kant's emphasis on the fundamental respect for the dignity and worth of the person is considered by many to be one of his most important contributions to the field of ethics. Persons are rational agents who can legislate moral laws and autonomously follow such laws. Therefore, persons should not be used as a mere means for our 'ends'; they should be treated with respect because of their dignity. As Kant (2002 p. 46) asserts, *"… rational beings … are called* persons*, because their nature already marks them out as ends in themselves, i.e. as something that may not be used merely as means … and is an object of respect …"*

Although Locke and Kant were not writing in the context of ethical issues affecting nursing and healthcare, their legacy continues to inform the conversation. For example, readers familiar with the discussion on the concept of person will inevitably meet the work of Peter Singer. He follows in the thought of Locke and applies it to healthcare today. Singer (1993 p. 87) considers a person to be a self-conscious, rational being. A person has a conception of him/herself as a distinct being with a past and with a future (Singer 1993 p. 91 and p. 131). According to Singer (1994 p. 218), a person is *"…a being with awareness of her or his own existence over time,*

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[13] See Chap. 2 for an outline of Kant's ethics.

[14] There are, of course, more ancient accounts on the concept of person that can be found in a variety of thinkers such as the Greek philosophers, Plato and Aristotle. However, contemporary ethical positions on the concept of person in bioethics and medical ethics are heavily influenced by Locke and Kant.

and the capacity to have wants and plans for the future." For Singer (1994 p. 206), it logically follows that not all persons are part of the *Homo sapiens* species and not all those who belong to the *Homo sapiens* species are persons. Singer's position is that the life of an embryo is not worth more than the life of a non-human animal at a comparable level of rationality and self-consciousness (Singer 1993 p. 169). An embryo is not a person in Singer's view. The same can be said of new-borns because they are not rational and self-conscious. Singer (1993 p. 169) continues further by claiming that *"if the fetus does not have the same claim to life as a person, it appears that the new-born baby does not either, and the life of a new-born baby is of less value to it than the life of a pig, a dog, or a chimpanzee is to the nonhuman animal."*

Another significant perspective on the concept of person is offered by Michael Tooley, who examines the concept of person as a descriptive term that is guided by moral concerns (Tooley 1983 p. 51). He discusses the subject of personhood in the context of having a right to life. The possession of self-consciousness is essential for him. His central contention is that *"an individual cannot have a right to continued existence unless there is at least one time at which it possesses the concept of a continuing self or mental substance"* (Tooley 1983 p. 121).

H. Tristram Engelhardt makes a distinction between strict and social concepts of person. Persons in the strict sense have moral rights and duties, whereas persons in the social sense only have rights (Engelhardt 1988 p. 177) . The strict sense of what a person is refers to agents who possess self-consciousness, rationality and moral agency (Engelhardt 1988 p. 175 and p. 178). On the other hand, the concept of person can be used as a social category which allows us to apply it to those who are not strictly persons. Entities who do not qualify as persons in the strict sense can be treated as persons in the social sense (Engelhardt 1988 p. 175). Engelhardt gives an example of infants who are not strictly persons but are treated as persons because of their social role. Normally infants are brought up in a social structure of a family and they take on a social role of a child to their parents and family (Engelhardt 1988 p. 176). It is as a result of their social relationships with those who are persons in a strict sense that we have persons in a social sense. The social sense of person can also be used to structure how those who are senile or profoundly intellectually disabled, for example, are treated (Engelhardt 1988 p. 176).

Others, however, would argue that personhood begins at human conception. The successful uniting of the sperm and ovum inevitably leads to a new entity that did not exist before. So it is argued as soon as we have a zygote, we have a person. For example, Joyce (1988 p. 199) contends that a human zygote is a person; however it is less developed. Lee and George (2005 p. 15) make the claim that persons "… are particular kinds of physical organisms." They go on to argue that a person is "… a distinct subject with the natural capacity to reason and make free choices. That subject … is identical with the human organism, and therefore that subject comes to be when the human organism comes to be, even though it will take him or her months and even years to actualize the natural capacities to reason and make free choices, natural capacities which are already present … from the beginning" (Lee and George 2005 p. 16).

However, this would be far from the dominant view in the literature which tends to deem embryos not to be persons. Even as far back as Joseph Fletcher's (1974 p. 5) seminal criteria, entities need to show certain characteristics. Fletcher lists fifteen positive characteristics, with the neocortical function being the prime one:

Minimal intelligence	Self-awareness	Self-control
A sense of time	A sense of futurity	A sense of the past
The capability to relate to others	Concern for others	Communication
Control of existence	Curiosity	Change and changeability
Balance of rationality and feeling	Idiosyncrasy	Neo-cortical function

The Potential Person

It is sometimes argued that although an embryo may not be a person, it is a potential person. Therefore, it should be given rights and the status of a person (although it is not a moral agent in the sense of being capable of making moral choices or being morally responsible). However the objection is often raised that the problem with claiming that an embryo is a potential person – and then giving it the status of a person with the fundamental right to life – is that there may be something premature in making such a claim. We would not normally give full status and responsibility of a qualified nurse to a student nurse, although we might say that a student nurse is a potential nurse. Joel Feinberg (1984 pp. 147–148) puts it very well with the following analogy: *"In 1930, when he was six years old, Jimmy Carter didn't know it, but he was a potential president of the United States. That gave him no claim* then, *not even a very weak claim, to give commands to the U.S. Army and Navy."* Therefore, it may not be enough to be a potential person to have the status and rights of a person, the individual needs to be an actual person.

Burgess (2010 p. 141) points to three types of potentiality. Firstly, there is 'passive receptivity'[15].

If it is accepted that an embryo has an active potential to become a person, then this potentiality is not something extrinsic but rather intrinsic to it. This would mean that stating that an embryo is a potential person is not the same as claiming that it is a potential nurse because the nursing is something that is extrinsic to the individual and does not define his/her very nature; the same could be said of any potential president.

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[15] Burgess' example is a piece of clay needing the guidance of a sculptor to become a statue; the clay needs something external to it to become a statue. Secondly, there is the example of 'interactive potency'. His example here is of sperm and ovum as the interactive potency in conception. Neither sperm nor ova have the potential by themselves to become an embryo. In the same way, neither of them alone is a potential embryo. Finally, there is 'active potency'. Burgess gives the example of an embryo having an active potential to become a child.

A further step can be taken by arguing that an embryo is a person with potential. As Joyce (1988 p. 199) contends, *"… every living individual being with the natural potential, as a whole, for knowing, willing, desiring, and relating to others in a self-reflective way is a person. But the human zygote is a living individual (or more than one such individual) with the natural potential, as a whole, to act in these ways. Therefore the human zygote is an actual person with great potential."*

Applying the Concept of Person to Nursing Practice (Including Case Study)

Although the concept of person may, for some, be very useful in debates about beginning and end of life issues, it might pose some difficulties for other nursing situations. Let us now consider a case below using the concept of person.

The Case of John

John O'Brien is an 81 year old man. After suffering a major stroke, he was admitted as an inpatient and has remained in hospital ever since. He has two sons and a daughter but they have not agreed on what will happen to him in the long-term. John is now suffering from severe cognitive decline, memory loss, and is very confused. He often talks about his wife as if she was still alive although she passed away two years previously. Sometimes he wants to go to work at a factory which he retired from many years ago. Every day, there is more and more evidence of his cognitive deterioration. He can't seem to remember which day of the week it is. One day, he was found staring at his own reflection in a mirror – it seemed that he didn't recognise the man looking back at him. Some days, John doesn't seem to recognise his own daughter, other days he does. The daughter says he is no longer the same. John is usually put to bed at about 9pm but does not want to go, he would rather go for a walk. When he attempts to get out of bed, he is gently put back in. Because he is trying to get out of bed the decision was taken to put him into a bed with bed rails. Now that John is getting more and more confused, his carers do not want him to go alone for walks even during the day. This has led to situations where John is in a chair for long periods of a time. A tray is kept in front of him and prevents him from getting out. For no apparent reason, one day John started to lash out at the nursing staff both verbally and physically. Now staff have resorted to using sedation which has had the side effect of more confusion, agitation, drowsiness and drooling.

Analysing the Case of John

The above scenario paints a broad picture of what can happen to those whose cognitive abilities and general competencies gradually deteriorate. Before looking at the case from the perspective of the concept of person, consider the following questions: What is wrong with John wanting to go for a walk at night, or wanting to get out of his bed or his chair? Is the reaction of the staff to John's behaviour perfectly reasonable or are they employing unreasonable institutional routines to deal with people whose cognitive capacities have deteriorated? Are the actions of the staff impinging on John's autonomy? However, is John autonomous anymore? Or more fundamentally is John a person anymore? As we have seen there is no really uniformed view of what makes an entity a person. However, if we accept the broad common denominators of self-consciousness, rationality and moral agency as the defining features of a person, this leads to an important question as to whether John is either beginning to lose his personhood or whether John is in fact no longer a person.

We saw that the philosopher Locke emphasised self-consciousness, thinking and reflection as defining features of a person. John's sense of himself and his ability to think is gradually deteriorating. Would we still consider John to be a fully thinking intelligent being? Does John continue to show reason and reflection? Can John really make rational decisions that are based on comprehension and understanding? Perhaps John can make some rational decisions (e.g. whether to go out for a walk), but have his cognitive abilities been compromised to such an extent that we would be still happy to claim that he is a rational, thinking being?

Is John the same person that he was 10 years ago? His daughter does not seem to think so. Does John still consider himself as a self? His own sense of his life's narrative in terms of a past, present and future is certainly compromised. Following Singer's work, can we consider John to be a being with awareness of his own existence over time, and having the capacity to have wants and plans for the future? Although John might seem to indicate a preference to go for a walk at night, it is difficult to ascertain if this is his actual wish. John does not seem to have the capacity any longer to have wants and plans for the future. On this issue, Singer (1994 p. 197) contends that, *"only a person can* want *to go on living, or have plans for the future, because only a person can even understand the possibility of a future existence for herself and himself."* It is difficult to envisage John having any future plans and it is unclear whether he can consider the possibility of a future existence for himself.

We saw that Kant emphasised an agency that is rational, autonomous and has the ability to act on moral principles. Can John discern moral principles and act on them in the Kantian sense? Can John take moral decisions and perform actions that display intentionality and consent? Would we hold John morally responsible for lashing out at the nursing staff? Probably not. On the other hand, while the lashing out can be explained as a product of John's cognitive impairment, it may not be. Even if John is evidencing cognitive impairment here, to the degree that he cannot be held responsible of this lashing out, it may not mean he is therefore generally incapable of moral thought, action, or decision making.

Overall, is John's level of self-consciousness, capacity for rationality and moral agency *enough* for him to be considered a person? Or is John a lesser person now because of his condition? Although John may (soon) no longer be a person in the strict sense of the word, to use Engelhardt's term, some may want to include him in the social sense of person. In this case, it may be claimed that John has no moral duties but he has moral rights. Some may want to claim that John has welfare rights.

He will still have a right to be cared for, he needs to be looked after in terms of subsistence, nutrition and hygiene.

Yet, claiming that someone like John is not really a person anymore (or less of a person) may appear counter-intuitive to nursing's endeavour to offer a caring response to the sick and vulnerable. The case of John reveals that one of the problems with using a concept of person is that it can have the ironic result of excluding many entities from this moral domain who we would normally think should be included.

My own thesis is that the lens of Henri Bergson's work on static and dynamic moralities (Bergson 1991) should be brought to bear on the concept of person to move the debate forward (Kearns 2007). Static and dynamic moralities generate two different types of social organisations: the closed and the open society. The closed society, with its static morality, is characterised by its close ties of social relationships and where its members care for their own group and exclude those outside its boundaries. The open society, with its dynamic morality, is characterised by a universal solidarity of the whole of humanity beyond the immediate concerns of any one social group. Dynamic morality defends a sense of solidarity for those beyond the social unit by an experience of a borderless love of universal humanity. It could be argued that certain concepts of person that exclude entities from this moral domain may inadvertently reflect, or become, the static morality of a closed society rather than the dynamic morality of an open society.

Should nursing ethics want to anchor a concept of person in a dynamic morality of an open society? If so, what would such a concept of person look like? An argument could be made that a dynamic morality would demand a sense of universal solidarity with all of humanity, and therefore with those who are most vulnerable in terms of health, stages of development and decline. It would require that the formulation of the defining features of a concept of person would need to be able to be wide enough to include vulnerable individuals who may not be able to look after or to advocate for themselves. A concept of person may need to be articulated from the perspective of those most vulnerable rather than from the perspective of fully developed articulate adults. This may lead to a more compassionate, rather than what often seems a clinical, view of personhood.

Conclusion

The concept of person can be employed when examining some of the ethical issues in nursing practice and healthcare. However, the concept of person has not yielded universal agreement when it comes to a definition and it has continued to generate numerous debates.

The concept of person can challenge us regarding both the purpose of nursing and healthcare practice and their scope; who is healthcare for? Should nursing and general healthcare only be for persons strictly defined? Should nursing and general healthcare be for social persons as well? With the increasing development of medicine and the limited resources available to meet expectations, such questions may become more and more pressing for nursing. Understanding how concepts of person and their ethical implications differ is important for nurses when engaging in discussions and debates with others about such questions. However, if the concept of person is used to offer a straight-forward framework for deciding on ethical issues in nursing, we need to be on our guard about this and keep in mind the famous statement by H. L. Menckent: *"For every human problem, there is a solution that is simple, neat, and wrong"* (cited in Huberts et al. 2008 p. 57).

Key Learning Points

1. The concept of human being refers to an entity who belongs to *Homo sapiens* species; whereas the concept of person is a moral (and metaphysical) category. Therefore, the concept of person can be applied to human beings and other entities that display certain characteristics.
2. The concept of person is sometimes employed in ethical debates about beginning and end of life issues. For example, an argument in favour of using embryos for research is to claim that they are not persons; an argument against using embryos for research is to claim that they are persons or potential persons.
3. Concepts of person – Some Key Points:
   - A. Boethius: Rational nature of the individual (substance)
   - B. Locke: Self-consciousness and capacity for thinking
   - C. Kant: Rational agent who can legislate moral laws and autonomously follow such laws
   - D. Fletcher: Fifteen positive characteristics with neocortical function being the prime
   - E. Singer: Self-conscious, rational being having plans for the future
   - F. Tooley: Possessing a concept of a continuing self
   - G. Engelhardt: Two senses of person – strict sense (possessing self-consciousness, rationality and moral agency) and social sense (category that can be applied to those who are not strictly persons)

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7 Patient Autonomy in Nursing and Healthcare Contexts

Anna-Marie Greaney and Dónal P. O'Mathúna

Abstract

Autonomy, and associated respect for patient autonomy, have gained increased prominence in nursing and healthcare practice in recent years. There is a growing understanding that patients have a right to self-determination and choice with regard to the care, support and treatment they receive. This right is supported by healthcare policy, enshrined in professional codes of conduct, and mandated by national and international legislation. However, while respect for patient autonomy, and associated patient choice, is accepted as a core tenet of professional practice, the actual reality of supporting autonomy can create tensions for nurses and other healthcare professionals. Such tensions arise when patient choice conflicts with professional advice, policy and best available clinical evidence. Respecting autonomy may, on occasion, lead to concerns regarding professional accountability and responsibility for patient welfare. This chapter aims to explore the complex reality of respecting patient autonomy in 'real-world' nursing and healthcare contexts. A case vignette is used to apply theoretical and professional considerations to a patient story; thereby highlighting some of the complexities regarding patient autonomy. The chapter explores autonomy in relation to the associated concepts of choice, freedom, decision-making, advocacy, professional accountability and legislative guidance. The chapter concludes by offering some proposals for reconciling professional accountability with respect for patient autonomy. These proposals draw on recent research, a more relational, as opposed to isolated, understanding of autonomy, and contemporary health and social care guidance.

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P.A. Scott (ed.), *Key Concepts and Issues in Nursing Ethics*,
DOI 10.1007/978-3-319-49250-6_7

Keywords
Autonomy • Professional accountability • Caring • Choice • Vulnerability • Human rights

Introduction: Autonomy and the 'Patient'

This chapter presents an overview of autonomy as a concept and explores the practical realities of respecting autonomy within nursing and healthcare contexts. While much of the chapter will explore different understandings of autonomy, some 'working' explanation of the concept is required at the outset. Autonomy, often referred to as self-determination, denotes an understanding of human beings as being worthy of respect. Being autonomous means that a person lives in accordance with his or her own values and wishes. To illustrate the practical dimensions of autonomy, a case study is included where the expressed autonomous wish of a patient, Laura, conflicts with the course of action that the nurse and others believe to be the most favourable. This case study facilitates a discussion on autonomy that is rooted in practice, and enables an exploration of various philosophical accounts of autonomy in the real, 'murky' world of every-day, patient-healthcare professional interaction.

The title of the chapter merits additional attention, as we believe the term 'patient' requires some defence from objectors. As health and social care systems have evolved, the understanding of the 'patient', and the meanings attributed to the term, have also developed. The terms 'person', 'client', and 'service-user' are now frequently used to denote the individual receiving care, support or treatment from health and social care professionals. Some may argue that the term patient places immediate limits on a person's will by confining them to pre-established power imbalances. While acknowledging the merits of this position in certain contexts, and the extent to which this debate could be extended beyond this account, we put forward three brief, interrelated claims, in support of using the term 'patient' in healthcare settings.

Firstly, we suggest that the word patient denotes a traditional, and worthwhile, understanding of a person in need of care, who is, as Sellman (2011 p. 51) suggests, '*more-than-ordinarily* vulnerable'. This degree of vulnerability, Sellman explains, is an extension of the vulnerability that every person as a biological entity experiences. In caring for the '*more-than-ordinarily* vulnerable' person, nursing has a specific aim to assist human flourishing by acknowledging and addressing such vulnerabilities. Secondly, the term patient counteracts the consumer-orientated relationship that terms like 'service-user' and 'client' promote. In the world of business, the client can be seen as the individual to be satisfied, but simultaneously clients are those to be managed and sometimes outsmarted in a market-based, capitalist society. In subscribing to a business model of the person-carer relationship, the threat of power imbalance may be hidden, but other professional ideals of care, compassion, advocacy and professional accountability may also be lost. Finally, we suggest that describing those we care for as patients will not create a power imbalance, but may serve to remind everyone of the potential for power imbalances. Misuse of power arises when those involved intend to use their power inappropriately, or fail to recognise the potential problems that power imbalances can create. We can have informed, involved, autonomous patients. These are people who require care but are '*more-than-ordinarily* vulnerable' and require due consideration in light of that vulnerability. In many ways, this understanding of the person as patient in nursing and healthcare contexts underpins the understanding of autonomy presented throughout the chapter. Respecting autonomy must involve an appreciation of vulnerability if healthcare professionals are to respect autonomy in an accountable way. We will return to this point as the chapter develops.

Defining Autonomy in Nursing and Healthcare Contexts

The term autonomy derives from the Greek 'autos,' referring to self, and 'nomos,' meaning law. A city in ancient Greece had 'autonomia' when the people established their own laws (Dworkin 1988). The emergence of individual autonomy is a more recent phenomenon. This is often attributed to Kantian philosophy. For Kant, autonomy is associated with notions of free will and reason that characterise humanity (1998). However, a Kantian understanding of autonomy is not a defence of isolated free choice, as is often assumed, but rather a way of living that is underpinned by duty and reason as opposed to individual desire.[1] In contrast, Mill's (1859) account of autonomy suggests that one's own liberty, or freedom of choice, remains paramount unless his or her autonomous choices cause harm to others. In accordance with Mill's position, we cannot interfere with the choices of others just because we feel those choices are unwise.

> The only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant (Mill 1859, p. 22).

While philosophical accounts of autonomy often present different perspectives, there is an understanding in more general usage that 'autonomy' is concerned with 'self-governance', 'self-rule', self-determination' and 'independence'. In short: 'I decide what happens to me'.

Autonomy in nursing and healthcare contexts is largely associated with free choice. The most recent code of ethics for nurses and midwives in Ireland outlines autonomy as, *"self-determination; a person's ability to make choices on the basis of their own values"* (Nursing and Midwifery Board of Ireland 2014). This is consistent with the 'right' to choice outlined by the International Council of Nurses Code of Ethics (2012), and the understanding of autonomy subscribed to by the nursing profession in other jurisdictions (American Nurses Association 2015). In this sense, registered nurses are duty bound to respect the autonomy of patients and respect

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[1] For further discussion of Kantian ethics please see Chap. 2.

their choices in the care setting. Interestingly, the recently updated code of ethics for nurses in the UK (Nursing and Midwifery Council (NMC) 2015), which outlines professional standards of practice and behaviour, does not contain the word 'autonomy'. While reminding nurses to value individual choice, it refers to a more shared approach to decision making. We will return to this later in the chapter.

The general emphasis on patient autonomy reflects a worldwide departure from traditional, 'doctor knows best' approaches, associated with paternalistic healthcare models. Medical dominance has now largely been replaced by patient autonomy. The growth of autonomy is, in part, the outcome of complex social change, but also owes much to the introduction of the four-principle approach to medical ethics (Beauchamp and Childress 2013). The four bioethical principles are autonomy, beneficence (to do good), non-maleficence (to avoid unnecessary harm) and justice (to treat people fairly). The principles collectively represent a middle-range theory of ethical decision-making. This theory suggests that actions are ethical if they accord with the principles. While there is continued debate about the merits of this approach, and the priority often attributed to autonomy, the principles have endured as a core foundation of bioethics, particularly in an American context. In their most recent, seventh edition, Beauchamp and Childress (2013, p. 101) define autonomy as follows:

> At a minimum, personal autonomy encompasses self-rule that is free from both controlling interference by others and limitations that prevent meaningful choice, such as adequate understanding.

Adhering to professional codes of ethics that adopt this view of a patient's autonomy would require that his or her choices should be respected, once the person is competent to make those choices. However, the perspectives of Kant (1998), Mill (1859) and Beauchamp and Childress (2013) suggest alternative, and partly conflicting, means of understanding and respecting autonomy in nursing and healthcare. Should we respect all choices based on free-will and reasoned understanding as Kant suggests? Should we respect any choice that does not result in harm to others regardless of how unwise it seems in accordance with Mill's perspective? What about choices that result in harm to one's self? Should healthcare professionals abstain from interference with the choices of patients as Beauchamp and Childress's definition suggests?

Difficult ethical decisions associated with autonomy and choice cannot be understood in isolation from the complex healthcare environments in which questions of choice arise. Laura's story, outlined below, presents a 'real-world' story of patient choice.

Autonomy in Context: Laura's Story

Laura is an eighty-year-old woman with a diagnosis of dementia. Laura has to this point lived at home with her 75 year-old sister Ann. Laura's dementia, and associated ability to carry out activities of daily living, have deteriorated significantly *over the last number of months. Laura's cognitive ability fluctuates on a regular basis. On occasion, she is quite disorientated, but at other times is able to converse easily and plan and engage in various activities. Laura is currently hospitalised following a fall at home sustained while attempting to climb the stairs. While no surgical intervention was required, Laura received a number of facial injuries and significant bruising. Laura has sustained other injuries recently including a burn. On another occasion, she fell on route to the downstairs bathroom and was found in a hypothermic state by her sister the following morning. Laura has been offered a place in a local community hospital, but has refused to move there, stating that she would prefer to die rather than leave her own home. Ann enjoys living with her sister, and is happy to care for her as necessary. However, she is frustrated that Laura will not agree to move to a downstairs en suite bedroom and is not prepared to endure further late night calls to the emergency services and a potentially fatal accident.*

Laura and Ann live in a small village with a good community spirit but do not have extended family living nearby. David, the nurse manager on the ward is engaging with Laura, Ann, the consultant geriatrician, the medical social worker and local public health nurse to plan discharge. David is aware that all nursing guidance suggests respect for personal autonomy (Laura's wish to stay at home and remain in her upstairs bedroom) but is unsure how to proceed in light of the range of associated factors.

- *What is David to do?*
- *How can we understand autonomy within the context of this complex range of factors?*
- *Is there a workable solution?*

Autonomy and Interference: Are they Compatible?

Given the various views about autonomy discussed above, we begin by questioning the assumption that respect for Laura's autonomy means that healthcare professionals abstain from interfering with her wishes so long as her choices are well informed and made with sufficient understanding. This depends on what we understand by 'interference'. Does interference involve questioning choices? Does it involve assessing understanding? Does it relate to persuasion? Alternatively, is the term interference confined to only those situations involving coercion? What do Beauchamp and Childress (2013) mean by 'controlling interference'? Recent empirical research suggests that while patients value respect for their autonomy in decision-making, they also prefer a more shared approach to decisions within a trusting relationship with care-givers (Schildmann et al. 2013). Some concerns have been expressed about an over-emphasis on a rights based doctrine of autonomy where notions of liberty and independence take precedence over considerations of care, trust and human connectivity in the care setting (Mol 2008; Harnett and Greaney 2008; Greaney et al. 2012).

Dooley and McCarthy (2012) support an interdependent approach in healthcare decision-making. The authors suggest that persuasion is legitimate in the patient-healthcare professional relationship, but that coercion and manipulation are not. They recommend a dialogical approach based on shared communication and professional engagement. This approach has also been advocated by recent research exploring patient autonomy in the context of patients who utilise self-testing technology (Greaney 2014). While we have some discomfort with the term persuasion, we argue that once any individual concedes to a course of action that he or she has previously refused, some degree of persuasion has taken place. This need not be coercion or manipulation, but rather a change of mind supported by information and engagement with the healthcare team and significant others. For example, health promotion involves a range of activities that essentially seek to educate, empower, encourage and eventually persuade people to alter their behaviour. Laura may be open to further engagement with David, the nurse manager, the wider healthcare team and her sister. Laura may agree, in essence, be persuaded, to move to a downstairs bedroom once she realises that this is important to her sister, and represents a significant step in supporting long-term care provision in her own home. Laura may be glad that David and others interfered with her initial choices through further engagement, explanation and deliberation. Conversely, Laura may not be open to further engagement and any form of dialogue or persuasion. A refusal to engage, or agree with proposals, must be viewed in light of her mental capacity and presenting healthcare needs. This is particularly significant when there is a risk of harm occurring to Laura. It is important that Laura understand the associated implications for her own well-being, for her sister, David and any others who are affected by her decisions. In the final analysis, once all dialogue has been exhausted, and the healthcare team are assured that Laura shows sufficient understanding of the consequences of her decision; she cannot be forced to do something against her will. (The determination of capacity will be explored in the law section that follows.) Regardless of the outcome, it is essential that the David, and other healthcare professionals, continue to engage with Laura and evaluative her care plan and the level of support in place.

We suggest therefore a 'middle ground' approach that legitimises some interference with personal choices but avoids coercion. The middle ground respects autonomy, and the choices of others, but recognises that other moral principles and obligations are at play. A middle ground perspective can arrive at solutions that respect autonomy and uphold professional accountability. An example of this middle ground approach is found in the Irish National Consent Policy to some extent (Health Service Executive 2013). This policy recognises an individual's legal and ethical right to consent to, and refuse, treatment in accordance with his or her personal autonomy. This extends to decisions that a healthcare professional may deem unwise. However, the policy (p. 20) proposes that respect for autonomy is not absolute.

> While respect for autonomy is very important, it is not the only ethical principle relevant to consent. Health and social care professionals also have a responsibility to try and maximise the health and well-being of, and to minimise harm to, service users and others.

This suggests that the moral obligations of healthcare professionals extend beyond an absolute adherence to patient autonomy where personal choices remain unchallenged. This is congruent with the competing duties outlined for nurses in professional codes of conduct, where obligations to respect autonomous choices co-exist with requirements to deliver safe, evidence-based care. This reflects an understanding of the patient-healthcare professional relationship outlined by Holm (1997). Holm undertook a grounded theory analysis of the moral problems experienced by nurses and doctors in practice. Holm coined the phrase "protective responsibility" to encompass the sense of professional obligation expressed by healthcare professionals when referring to their moral deliberations (1997, p. 127). 'Protective responsibility' relates to the healthcare professional's awareness of the vulnerability of the patient, by virtue of their ill health, and the relevance of non-maleficence in the ethical decision-making process. Healthcare professionals outlined the significant roles they played as partners in the decision-making process.

Chiovitti (2008) explored the meaning of caring among 17 nurses engaged with patents in a psychiatric setting. In a similar manner to Holm, Chiovitti concluded that caring was expressed through the psychological process of 'protective empowering'. Protective empowering involved a series of care interventions. While nurses sought to empower patients to become more actively involved in their health, considerations of patient safety were also significant.[2] The concepts of 'protective responsibility' and 'protective empowering' are central features of this middle ground approach to reconciling respect for autonomy with other professional obligations. We suggest that this 'protective' sense underpins David's indecision with regard to Laura's care. Knowing that Laura's autonomy is respected is not sufficient for David. His knowledge of Laura, her specific health issues and the possible consequences of her choices prompt further reflection and action.

As noted earlier, the UK Code of Ethics reflects this middle ground to a greater extent than guidance for nurses in the USA or Ireland. The UK Code (NMC 2015) refers to shared decision-making as opposed to endorsing autonomous decision-making. The Code directs nurses to *"empower people to share decisions about their treatment and care"* (p. 5). The Code also acknowledges that not every patient strives for autonomy and independence in decision-making. It outlines the need to *"respect the level to which people receiving care want to be involved in decisions about their own health, wellbeing and care"* (p. 5).

Tauber (2005) appreciates the challenges that sometimes exist for healthcare professionals when promoting patients' autonomy and choices. In *Patient Autonomy and the Ethics of Responsibility*, Tauber calls for a *"humane medicine"* (p. 43) underpinned by a more psychosocial understanding of the patient's story. Tauber urges healthcare professionals to return to a covenant model with patients, where autonomy and beneficence become mutual supports as opposed to adversarial concepts. This type of model, in contrast to a conventional contractual model, promotes

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[2] For further discussion of such ethical issues within the context of mental health nursing please see Chap. 11.

responsibility "*in alignment with the claims of autonomy*" (p. 19), and avoids more business-like relationships. In this sense, professional responsibility/accountability for patient welfare and respect for autonomy can co-exist in a shared model.

This approach is congruent with the philosophical foundations of nursing and the significance of caring as a central component of what nurses do. Nurse theorists may debate the constituents of care, but the concept of care remains the most dominant characteristic of the nurse-patient relationship. From a moral theory perspective, the ethics of care as expressed by Gilligan (1982) and others[3] echoes the need to move beyond impartial moral rules related to duty and consequences, and understand the nuances of the human condition. In comparison to rule-based moral theories, an ethics of care is rooted in relatedness and connectivity. Mol (2008, p. 43) articulates the difficulties that can exist in healthcare when a pronounced focus on personal autonomy and choice exist. Mol's central thesis is that a 'logic of choice' is not consistent with a 'logic of care' and may lead to 'poor' care. For Mol, while the logic of choice is concerned with patients as customers and autonomous, independent individuals, the 'logic of care' suggests a far more messy landscape. In accordance with Mol's analysis (p. 62) *"the logic of care is attuned to people who are first and foremost related"*. As Laura's nurse, David is not solely preoccupied with a duty to respect her autonomy. He is aware of his connection to Laura, his responsibility and accountability for her welfare, and a philosophy of caring that is central to his role. We have previously articulated the significance of care, relationality and responsibility as an alternative to a libertarian focus on personal choice and independent decision-making (Greaney et al. 2012). We do not suggest a return to paternalism by another name, but rather that healthcare ethics is not reduced to an unquestioning adherence to autonomy, to the detriment of other moral principles and wider professional considerations.

Autonomy, Capacity and the Law

For the most part, the law internationally respects an individual's right to autonomy in the context of healthcare decisions. A competent individual has the right to consent to, and refuse, treatment even if such a refusal results in death. This right is enshrined in both constitutional and case law in many jurisdictions and has a distinct human rights dimension. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD 2006) asserts the specific rights of people with disabilities to have legal capacity on an equal basis with others, and an associated right to make decisions that reflect their personal will and preference. Member states are obliged to provide the supports necessary to enable people with disabilities to make their own decisions. One cannot be presumed to lack capacity to make decisions based on a specific diagnosis or disability. In accordance with the Convention, a previously established approach of substituted decision-making, based on the perceived best interests of the person, is now replaced by an appeal to

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[3] For an introduction to the ethics of care please see Chap. 5.

personal will and preference. In essence, the paternalistic approach of *deciding for* is no longer supported by international law. In Ireland, the recently enacted Assisted Decision-Making (Capacity) Act (Government of Ireland 2015) will enable the formal ratification of this Convention and provides practical steps towards its implementation. The Mental Capacity Act in the UK (Department of Health 2005) shares many similarities with the Irish legislation but also has significant differences. This relates to the fact that the capacity legislation in the UK pre-dates the UNCRPD (2006).[4]

The Assisted Decision-Making (Capacity) Act (Government of Ireland 2015) asserts the principles of the UN Convention in many respects. The legislation reforms the law for people who require assistance, or may require assistance, to make their own decisions. It underlines the presumption of mental capacity and the rights of people to make decisions that others may consider unwise. The act refers to a series of supportive measures to assist individuals to make their own decisions, and applies a functional assessment of capacity to determine if people are competent to make their own decisions. In accordance with the legislation, Laura has a right to legal capacity (the right to make legal decisions), and a presumption of mental capacity (the ability to make a decision), irrespective of her diagnosis of dementia. This is fundamental to how David, and other members of the healthcare team, should interact with Laura. She cannot be deemed unable to make her own decisions unless all necessary efforts have been made to facilitate her understanding. In accordance with the law, Laura may appoint somebody to assist her with decision-making or nominate an enduring power of attorney. This person may be her sister, another relative or some other individual. Whether she had previously nominated such a person would need to be established.

A central issue in Laura's story is her mental capacity to make the decision to stay at home. The functional assessment of capacity (adhered to in Ireland and in the UK) is time and decision-specific. In accordance with the Irish legislation, Laura has the necessary capacity to make the decision to stay at home if she understands information relating to the decision, is capable of retaining this information, can weigh up the associated issues (including the risks of staying at home or staying in an upstairs bedroom) and can communicate the decision.

In summation, the UNCRPD (2006) would attach significant weight to Laura's personal will and preference, even if the healthcare team believe her decision to stay at home is unwise and may cause her harm. In terms of contemporary capacity legislation, the functional assessment may determine that Laura does or does not demonstrate the mental capacity to make this particular decision at this time. If Laura is deemed to lack mental capacity, then measures could be legally applied to maintain her safety, including possibly her detainment in a nursing home against her will. If Laura is determined to have mental capacity, then her decision to stay at home

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[4] A more detailed review of the differences in legislation is beyond the scope of this chapter. For an overview of debates regarding the compatibility of capacity legislation in the UK with UNCRPD (2006) see, The Essex Autonomy Project position paper, *Achieving CRPD Compliance* (2014), available at http://autonomy.essex.ac.uk/uncrpd-report

should be respected. However, in accordance with the full ethos of the UNCRPD (2006), healthcare professionals should not rush to capacity assessments in an attempt to 'force' people to comply with what the healthcare team believe is the best course of action. The convention obliges healthcare professionals to work with people and support their decision-making, even if those decisions cause some unease. We do not suggest here that all personal preferences can be supported. However, we do suggest that a genuine respect for the choices of others is important and that energies are invested in realising those choices in creative, sometimes safer, ways as opposed to challenging them.

Ideally, a form of advance care planning would be in existence, which could have evidence of Laura's preferences with regard to living arrangements. This approach is particularly relevant in the context of individuals with dementia whose mental capacity will deteriorate over time. Notwithstanding the legal issues that arise in this case, and how they may be resolved through capacity assessments or even the courts, a number of professional and ethical concerns remain for David. Despite agreements that may be reached in accordance with the law (restrictive or permissive), David's commitment to Laura's welfare, and his sense of professional obligation, may result in him experiencing moral distress. Moral distress arises when our actions, or the prevailing actions of those around us, do not accord with our moral convictions. In keeping with the middle ground approach, we propose that there may be ways in which Laura's preference to stay at home and her safety can both be realised through a process of engagement and negotiation. We will discuss these further below. This way of working is far more appealing, and we suggest more ethical, than 'abandoning' people to the hazards of their own choices under the guise of autonomy, or alternatively applying restrictive practices, even if supported by the law.

Autonomy and Others: Relational Autonomy

In addition to the Kantian and Millian perspectives on autonomy outlined earlier in this chapter, another understanding embodies the concepts of care, relationality and responsibility that we have articulated. This is relational autonomy. Relational autonomy is described as an umbrella term for approaches that value the *"role social relations play in the development and exercise of autonomy"* (Ashley 2012, p. 19). Relational autonomy acknowledges that we do not live in isolation and that our decisions reflect our interactions with, and obligations towards, others. If we consider our plans for the weekend, our autonomous choice, our will and preference, may be to spend it at home by the fire catching up on our favourite television series. How often does this materialise? Dependent on our circumstances, there may be numerous other activities and obligations that require our attention. In reality, we meet the obligations of our busy lives and negotiate a pathway between what we want to do, the needs of others and what we actually do. This raises questions about the extent to which exercising our autonomy reflects our basic desires to do what we want (stay home and hibernate perhaps) or the type of person we want to be (an individual committed to helping others). This relates to the philosophical distinction between liberty, or freedom, and autonomy.

Dworkin (1988) makes this distinction and explains that autonomy is sometimes misunderstood as synonymous with freedom. For Dworkin, *"autonomy is a richer notion than liberty"* and relates to being *"more than a passive spectator of one's desires and feelings"* (p. 107). We can extend this understanding of autonomy to dieters who are not free to eat what they want to meet their broader goal, their more considered autonomous wish, to lose weight. Autonomy is not about freedom to act independently in ways that fulfil our own desires. Relational autonomy reflects the fact that we live in a world with others and make decisions in this context. In Dworkin's analysis, an isolated, independent understanding of autonomy *"makes autonomy inconsistent with loyalty, objectivity, commitment, benevolence and love"* (p. 21). Relational autonomy acknowledges that individual autonomy fails to capture the interdependent nature of our lives. Relational autonomy is often associated with feminist philosophy but is also subscribed to by communitarians. A libertarian understanding of autonomy that is rooted in individualism is predominantly a westernised phenomenon. Alternative cultures look to others in the decision-making process, both in healthcare and other contexts.

This understanding of relational autonomy embodies David's unease with adhering to Laura's choices without interference. It is this sense of relational autonomy that underpins his concern for her welfare and his attempt to influence her to review her decision. However, relational autonomy also suggests that Laura consider, or be encouraged to consider, the impact of her decision on her sister, Ann. If Laura endures an injury, Ann is called upon to help. Ann lies awake at night wondering if Laura will fall and has to contact the emergency services should an injury occur. David should bring Ann's perspective into his interactions with Laura. This should be part of an open conversation about the impact of Laura's choices on others. In addition, David needs to consider Laura's request from a broad range of perspectives, not just safety. There is a need for some negotiation on all sides.

Autonomy Solutions in Contemporary Healthcare Practice

We need to move towards a practical resolution of Laura's story and return to our original questions. What is David, as a registered nurse and nurse manager to do? How can we understand autonomy in this complex range of factors that Laura's story presents? Is there a workable solution? We suggest that the answer to all three questions lies in a relational, interdependent understanding of autonomy that demands more than a recourse to capacity assessments in times of disagreement. Contemporary healthcare practice is developing an increasing awareness of the complexities involved in respecting autonomy in the care setting. This is partly due to the growing significance of personal autonomy in the law as outlined above. Recent empirical evidence suggests that the day-to-day nuances of practice reflect a more complex reality of autonomy than a functional assessment of capacity can provide. Autonomy, as explained in the previous section, goes beyond, *I decide* *what happens to me*, and involves our relationships with, and obligations towards, other people. We advocate this 'middle ground' approach in this chapter as an alternative to more libertarian perspectives on autonomy. Some contemporary examples explain what this approach means in the practice setting.

A recent phenomenological study explores the meaning of autonomy in people who use self-testing devices to measure their blood glucose levels (Greaney 2014). The participants' experiences of autonomy reveals an understanding of autonomy as an interdependent and context dependent process - *Autonomy as Lived*. This 'process' involves mutual respect and understanding between patients and professionals and is not confined to discrete moments of choice. For participants in the study, autonomy in their everyday lives is contingent on personal issues related to: the overall stage in their illness trajectory; their experiences of chronic illness; their willingness to take an active role in the management of their own health; and their ability to understand and master a technological device. Phenomenological analysis revealed the sub-theme, *Autonomy within constraints*, to signify the somewhat diminished sense of autonomy experienced by people when living with a long-term illness.

Interdependence is evident in the participants' accounts of living with diabetes and the self-testing process. Engagement, interference and influence from others, often rejected in a libertarian, isolated sense of autonomy, are seen not only as permissible, but necessary to enable more autonomous living. *Autonomy as Lived* reflects a relational understanding of autonomy, as previously explained in this chapter, and is congruent with Sellman's (2011) understanding of patients as people who are '*more-than-ordinarily* vulnerable' and merit consideration in this regard. This contextualised, interdependent understanding of autonomy has previously been articulated in phenomenological accounts of older adult care settings (Agich 2003).

Greaney (2014) proposed *Negotiated Autonomy* (Fig. 7.1) as a process to address the tensions experienced in healthcare when an individual's choices conflict with healthcare professionals' moral intuition and professional obligation to provide safe, evidence-based care. *Negotiated Autonomy* recognises autonomy as relational and occurring in the real world, where actual autonomy may be different from ideal autonomy (Agich 2003). It appreciates more substantive accounts of autonomy and recognises that while patient decisions may be rational, this is not sufficient to accept them without question. It supports a 'logic of care' as opposed to a blind adherence to a 'logic of choice' (Mol 2008). It is compatible with the 'middle ground' approach suggested within this chapter. *Negotiated Autonomy* does not condone coercion but is underpinned by mutual respect and understanding. *Negotiated Autonomy* allows the concepts of care, responsibility and relationality to be realised. In Fig. 7.1 below the various elements of *Autonomy as Lived,* presented in an anti-clockwise direction are: Openness to negotiation, Respect for autonomy, Respect for the other story, Acceptance of personal responsibility, and a commitment to Dialogical practice. While an individual retains his

Fig. 7.1 Negotiated autonomy

or her autonomy, it is in exercising that autonomy that negotiation occurs; in the decision-making process.

The starting point is being *open* to negotiation. It is important that all stakeholders are open to this negotiation. If not, the process becomes a covert means to 'force' patients to conform. In Laura's story, negotiation may involve Laura agreeing to move to a downstairs bedroom, as opposed to the community-nursing unit. During negotiation, David, others in the healthcare team, and Laura's sister Ann may accept the degree of risk this entails. This approach is congruent with positive risk assessment, which acknowledges the role of risk in living fulfilled lives. Positive risk management seeks to identify risks and minimise those risks in ways that maximise the potential and priorities of the person involved (Morgan 2010). In this sense, healthcare professionals are engaged in positive risk assessment as opposed to risk avoidance. This is congruent with defining non-maleficence as avoiding *unnecessary*, as opposed to *all,* harm. Beauchamp and Childress (2013) explore the concept of harm and note that nonmaleficence obliges us to justify harmful actions. In this scenario, appealing to Laura's preference to stay at home, and the associated impact on quality of life, could justify the possible harms that may arise in the absence of further supervision in a nursing home context. Harm could be reduced by use of a sensor mat that would alarm and alert Ann, should Laura leave her bed during the night. Respect for autonomy involves respecting the rights of others to make decisions on matters affecting them and have those decisions respected. This respect for autonomy may involve what Olsen (2003) refers to as the 'ethical use of influence' to encourage people to make healthier, safer choices. For Olsen, influence is an ongoing feature of patient-healthcare professional interaction. It involves a relational approach whereby every action of influence, despite its magnitude, is assessed for its ethical suitability. This assessment can occur through a process of self-reflection where the healthcare professional explores his or her actions and underlining motivations. David can respect Laura's autonomy but also seek to influence her initial decision to sleep upstairs and prompt her to understand the risks involved and the consequences for her, and her sister.

Respect for the other story involves both patient and healthcare professional appreciating the other's perspective. In Laura's story, this involves David, and other professionals respecting the significance of Laura's preference to remain in her own home. It also involves Laura understanding her sister's predicament, as well as the concerns of healthcare professionals and their professional obligations to promote her well-being. Acceptance of personal responsibility is also a mutual task. David acknowledges his responsibility for Laura's care and the level of support she requires, while Laura accepts personal responsibility for her health and well-being, in so far as her fluctuating capacity allows her to do so. *Dialogical practice* involves moving beyond a contractual account of the caring relationship, to working in ways that engage with personal narrative (Brody 2002) and promote a genuine sharing of language, knowledge and beliefs. In this sense, David would engage with Laura to understand her choices and associated motivations and seek ways in which they could be realised without over-compromising her safety.

A comparable staged approach to balancing respect for autonomy with professional accountability is found in recent guidance from the Health Information and Quality Authority in Ireland (HIQA 2016). The guidance draws on Autonomy as Lived (Greaney 2014), similar relational accounts of autonomy and positive risk assessment strategies to facilitate patient autonomy in an accountable way. Central to the guidance is *A framework for good practice in promoting people's autonomy when using health and social care services* (See Fig. 7.2). The framework was developed in association with key stakeholders groups using action-learning methodology and therefore reflects the realities of everyday practice. The framework is compatible with a human rights approach to supported decision-making (UNCRPD 2006), with its starting point being respect for the legal and mental capacity of persons and their right to make decisions about matters that affect them. Avoidance of pre-judgement on autonomy is a core element of the framework as is respecting autonomy regardless of diagnosis. The framework also encourages person-centred communication and a balancing of rights, risks and responsibilities in accordance with positive risk assessment. The framework instils the importance of person-centred supports and the need to evaluate their efficiency. The guidance document (p. 59) includes a self-reflection checklist for health and social care providers to self-assess the extent to which they support autonomy in their daily activities. This will allow healthcare professionals to determine if they are engaged in the 'ethical use of influence' (Olsen 2003), as noted above, or more coercive strategies.

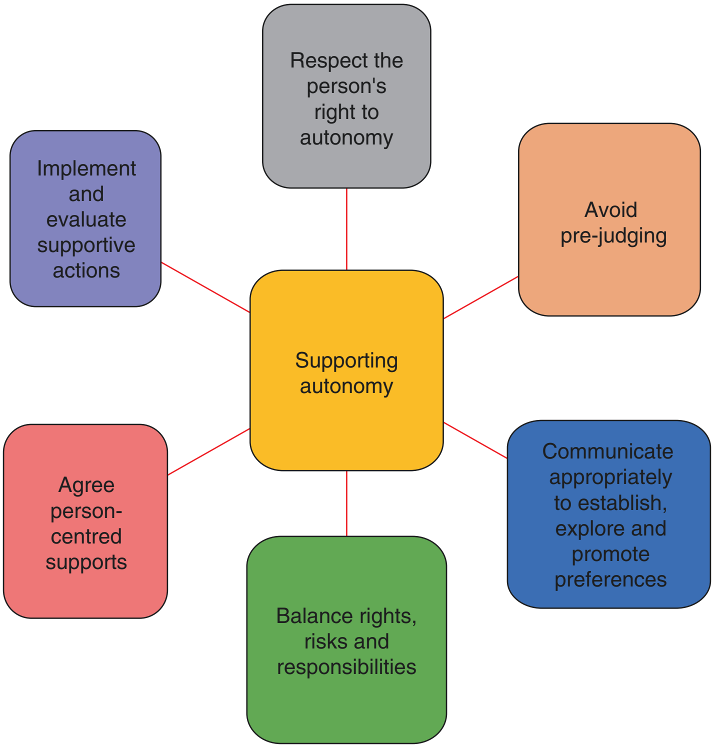

Fig. 7.2 A framework for good practice in promoting people's autonomy when using health and social care services (Reproduced from HIQA (Ireland) 2016)

Conclusion: Autonomy, Accountability and Laura

Laura's story may reach a favourable conclusion through a relational understanding of autonomy that reflects the interconnected, contextual nature of our daily lives. An approach that values personal autonomy, person-centred communication and supportive practices can achieve a balance between Laura's expressed preferences and David's professional accountability for her care. A process of dialogue and negotiation could result in Laura agreeing to move downstairs. Dialogue and negotiation should not assign lower priority to her personal will and preference, but facilitate her personal choices to be explored with her in light of the risks they pose and their impact on others. The movement to a downstairs bedroom will not eliminate risks entirely. We recognise the importance of risk in human flourishing and appreciate that quality of life involves more than keeping people safe. A range of person-centred supports can minimise the risk of harm occurring. This approach may avoid the need for capacity assessments which provide a legal basis for action, but may also instil fear and mistrust if '*more-than-ordinarily* vulnerable' (Sellman 2011) people are legally bound to submit to restrictive practices.

We suggest that the approach presented here is more compatible with a human rights agenda and the ethos of the UN Convention as it seeks to engage with people in ways that are least restrictive. Through a process of real engagement, David can act as an advocate for Laura and comply with his professional obligations as a registered nurse.

Key Learning Points

1. Autonomy is concerned with respect for persons, their values, preferences and choices.
2. In nursing and healthcare contexts, the patient has a right to autonomy and the associated right to make choices that accord with his or her personal values.
3. Respecting autonomy can create challenges for healthcare professionals when patient choice conflicts with best available evidence and promotion of health, safety and wellbeing.
4. A middle-ground approach that values the concepts of care, relationality and responsibility, in addition to autonomy, can provide some solutions.
5. This chapter outlines some contemporary perfectives on autonomy that reconcile the principle of autonomy with other moral and professional principles through a process of engagement and negotiation. This middle ground approach values autonomy yet also recognises the vulnerability of patients in the care setting.

Acknowledgement The authors would like to acknowledge the contribution of Professor P. Anne Scott as co-supervisor on the referenced PhD work. The PhD study was partly funded by the School of Nursing and Human Sciences, Dublin City University and Science Foundation Ireland (SFI) (SFI 05/CE3/B754 and SFI 10/CE/B1821). Acknowledgements are also extended to personnel at the Health Information and Quality Authority (Ireland), and the wider project team members, for their insights during participation in the Autonomy Guidance project. Finally, we thank the many patients, health and social care professionals and academic colleagues whose comments and experiences have contributed to the ideas presented.

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The Nurse as Patient Advocate?

8

P. Anne Scott

Abstract

The need to act as an advocate for the patient, as an important part of the nurse's role in the 21st Century, appears to be taken for granted; this is especially the case in the nursing literature, and in the British, Irish and international nurseing practice contexts. However while some nurse scholars, nursing registration bodies, professional organisations, and many practising nurses seem quite happy with the rhetoric of 'nurse as patient advocate' this is not an uncontroversial stance. A number of authors have challenged both the basis for the claim that nurses should be patient advocates, and the possibility of such a role for nurses.

Given that claims to the advocacy role for nurses are continuing to appear both in our literature and in our codes of practice it seems relevant to ask what the notion of nurse advocacy means, and what are the relative strengths and weaknesses of claims for and against an advocacy role for nurses.

Keywords

Advocacy • Nurse advocacy • Nursing role • Codes of practice • Patient advocate

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P.A. Scott (ed.), *Key Concepts and Issues in Nursing Ethics*,
DOI 10.1007/978-3-319-49250-6_8

Two Case Studies

Alice

Alice, a 12 year old girl, is admitted to her local paediatric hospital with a history of "pins and needles" and loss of power in her right hand and right leg. Staff observation reveals apparent loss of power and sensation in the girl's right hand and arm. She also has reduced sensation and power in her right leg which she tends to "drag" when she is encouraged to walk.

Following a number of examinations by various specialists, a battery of blood tests, X-rays and ultrasound, that required the removal of the brace from Alice's teeth, the initial diagnosis of multiple sclerosis, followed by a variety of other neurological conditions, are ruled out and "functional disorder of unknown origin" is the working diagnosis.

Alice's immediate family – 14 year old brother and parents - are very concerned, attentive, and visit regularly. Alice is frightened. She has no idea what is wrong with her or what is happening. The nurses pop into her room a few times a day – to make her bed, take her temperature and so on. The doctors come and go. The physio has also been to have look at her. The only person who really talks to her from the hospital is the really nice lady who brings the food. She recognised pretty quickly what Alice does and does not like to eat and saves Alice little treats and the peach yogurt that Alice loves. Alice feels home sick and no-one seemed to know when she will get home.

Mr. S

A middle aged man is admitted to the medical unit via the Emergency Department (ED) with severe dyspnoea, coughing and distress. The patient is 6 days post transurethral prostatectomy (TURP). His surgery and immediate post-operative period was uneventful and Mr. S was discharged home on the third post-operative day. Over the following days he becomes increasingly breathless and is referred by his GP to A&E as an emergency, The GP suspects that Mr. S has developed a pulmonary embolism (PE).

Following initial assessment in ED, Mr. S is given iv antibiotics, placed on oxygen via nasal catheters and eventually transferred to the medical ward to await a scan to confirm the initial diagnosis of PE. Mr. S is accompanied by his wife. Shortly after arrival on the ward Mr. S is admitted by a pleasant nurse and told that the doctor would be along to see him. As it is now 9.30 pm he will not be sent for the scan until tomorrow (Saturday).

Approximately 30 minutes later the Registrar arrives and following a cursory conversation and "look" at Mr. S the Registrar says that probably Mr. S has a "clot on your lung" and he will "put" Mr. S on warfarin. Mr. S's elderly uncle, who lives in Scotland and who had been on warfarin for many years, has just been taken off Warfarin and put on a newer drug that his doctors said was more effective and had fewer side effects. Therefore in response to the Registrar's comment that he will put Mr. S on Warfarin Mr. S and his wife ask what exactly the Warfarin is for and if there *is not alternative, newer drugs with fewer side effects? The Registrar indicates again that Mr. S likely has a clot and that this needs to be treated. Mr. S and his wife explain that they just want more information about Warfarin and what the alternatives are. The Registrar says that this is fine, he will speak with the Consultant, and come back to Mr. S.*

Sometime later the night nurse comes around and speaks to Mr. S as she is doing the nightly medicine round. She says "I hear you have refused medication". Mr. S tries to explain that he has not refused medication he has simply asked for information on Warfarin and what the alternatives are. The following morning the Consultant comes to visit Mr. S. She has also been told that Mr. S has refused his medication…

Introduction

25 years ago Allmark and Klarzynski (1992, p. 33) suggested that *"The notion that nurses either are, or should be, patient advocates now seems to be part of the nursing cannon."* However, while some nurse scholars, for example Tomaschewski-Barlem et al. (2015), nursing registration bodies (Nursing and Midwifery Board of Ireland (NMBI) 2014), professional organisations (American Nurses Association (ANA) (2015), and many practising nurses seem quite happy with the rhetoric of 'nurse as patient advocate' this is not an uncontroversial stance. Many authors have challenged both the basis for the claim that nurses should be patient advocates and indeed the possibility of such a role for nurses (Allmark and Klarzynski 1992; Seedhouse 2000; Negarandeh et al. 2006).

Advocacy: Some Definitions

In order to begin to explore this notion of the nurse as patient advocate, and to assess the relative strengths and weaknesses of the arguments, it is useful to look at how the term 'advocacy' is used in the nursing literature.

In a seminal article on advocacy in nursing Curtain (1979, p. 2) distinguished her notion of advocacy in nursing from the legal concept.

> The concept of advocacy implied here is not the concept implied by the patient rights movement, not the legal concept of advocacy, but a far more fundamental advocacy founded upon the simplest and most basic of premises … our common humanity.

Bandman and Bandman (2002, p. 23) states of nurse advocacy:

> The nurse who understands the advocacy role promotes, protects and thereby advocates patient interests and rights in an effort to make them whole and well again.

This statement does not really enlighten us as to the meaning of advocacy in the nurse-patient context. It also raises the question, "Is there anything here particular to the nursing role?"

Seedhouse (2000) distinguishes between what he terms “the normal sense of advocacy” and “the nurse theorist sense of advocacy”. Seedhouse claims that

> In everyday use advocacy is a simple notion. An advocate speaks on behalf of some other person (or persons)... On this sense an advocate supports people by taking their side directly.
>
> An advocate in the normal sense cannot be impartial. She must take the part of the person for whom she is advocating. If she tries to take a balanced view, or advocates what she thinks, rather than what her client wants, then she is not advocating in the normal sense. … The nurse theorist sense of advocacy is considerably broader than the normal one…
>
> In contrast to the normal sense, the nurse theorist understanding is that an advocate supports people by providing, or helping them obtain some of their basic human needs. Both the normal and the nurse theorist… agree that advocates support other people, but the nature of this support is different. On the normal sense the advocate says:
>
> ‘You’re not getting what you want, would you like me to back you up as you try to get it? … But on the nurse theorist sense the advocate says: ‘You have some fundamental problems. Let me sustain you as much as I possibly can’ (Seedhouse 2000, p. 16–17).

Seedhouse’s description of the ‘nurse theorist sense’ of advocacy seems in keeping with the notion of advocacy as expressed by theorists’ such as Curtain (1979), and bodies such as the NMC (2015), NMBI (2014) and ANA (2015). Conversely Seedhouse’s ‘normal sense’ of advocacy is in keeping with the definition of advocacy expressed by a number of authors such as Allmark and Klarzynski (1992) and by the Citizens Information Board, Ireland (CIB) (2015).

> Advocacy is a means of empowering people by supporting them to assert their views and claim their entitlements and where necessary representing and negotiating on their behalf (CIB 2015, p. 1).

We appear to have two different conceptualisations of advocacy being expressed here. In order to decide which one is most reasonable one may be driven to ask “What is the core *meaning* of the concept ‘advocacy’?” According to Paley (1996) we can only come to a reasonable level of clarity regarding what ‘advocacy’ means if we locate the term within a particular theory. For example this might be a theory of nursing- or nursing interventions - or caring or patient need. If we accept that one of the foundations of nursing is the requirement to provide safe, humane, holistic, good quality care to our patients (Scott et al. 2014) then it seems important to ask what our patients may require, in terms of advocacy, from the nurse caring for them?

The Patient Experience

For the purposes of this chapter ‘patient’ is taken to refer to an individual hospitalised or in institutional care due to mental or physical illness or disabilities; people like Alice and Mr. S described in the case studies at the beginning of this chapter, for example. One might usefully ask ‘Why would such an individual need an advocate’? Why would a patient need support, information, or someone to speak up for him or her?

It seems that there are at least two possible reasons that a hospitalised patient might need someone to fulfil an advocacy role:

1. Illness is likely to cause an individual distress, increased vulnerability, and dependency. Knowledge deficits and / or institutional structures and processes may also mean that the capacity of the individual to make informed decisions regarding appropriate treatment is curtailed or undermined. These kinds of issues are clearly at play when one considers the types of situations Alice and Mr. S find themselves in.
2. A second reason that a patient may be perceived as requiring a patient advocate to work on his / her behalf, is the power imbalance within the practitioner - patient relationship; and the fear that this imbalance will result in an undermining of patient autonomy. The more powerful clinician, guided by the principle of beneficence (doing good / working in the patient's best interests), may fail to recognise that the nature and content of 'good' may be understood differently from the practitioner and patient perspectives. There is increasing evidence that patients and practitioners may differ both in perceptions and priorities regarding patient care (Papastavrou et al. 2011). What a clinician perceives to be in the patient's best interests, from a health perspective, may not be accepted by the patient as being in his / her overall best interests; something which a smoker or a mountain climber might readily accept for example. However, because of the power imbalance the patient's voice may not be either sought or listened to. Thus the patient may have little ability to influence his / her care or treatment, unless he / she has recourse to a patient advocate. Again this power imbalance does seem to be a factor in both the scenarios describing Alice and Mr. S's experience of hospitalisation. Alice is isolated, lonely, and home sick. There is no sense from the case study that any nurse has developed a relationship with her or is helping Alice understand what is planned for her care, discharge, and so on. Mr. S and his wife simply want information and a clear explanation regarding why Warfarin is the drug of choice in this case. Yet their entirely reasonable concerns are not being addressed – or are being misunderstood. Mr. S is being labelled as "refusing treatment". Unintended intimidation can be the result of health care worker / patient encounters. Even the most outspoken and educated can be impacted by the "expert". This is a particular concern when one considers that many patients in acute hospitals tend to be older, with lower levels of education. There is a clear risk that they lose their voice.

   The need and right which both Alice and Mr. S have for information regarding their treatment and care is being ignored – as is their need and right to participate in decision-making about their care. Both information and being enabled to participate in choosing options and decisions regarding his / her care are key elements of respecting patient autonomy.[1]

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[1] Please see Chap. 7 of this book for further discussion of patients' autonomy.

It seems that the concerns regarding the lack of recognising and supporting patient autonomy expressed in the cases above, in combination with recent investigations and reports from both the Department of Health in England and Wales (Francis 2010) and the Irish Health Information and Quality Authority (HIQA 2015), give sufficient reasons to accept that the need for a patient advocate may be a reality, for at least some patients within the healthcare setting.

The question then arises as to who would make an effective patient advocate? A further question is "Why do many nurses and nursing bodies suggest patient advocacy is an aspect of the nursing role?"

Some Arguments in Favour of an Advocacy Role for Nurses

There are arguments presented in the literature both for and against nurse advocacy. Among those cited in favour of the nurse as appropriate advocate for the patient are the following:

1. Patient rights need protecting. Part of the nursing role is to support, sustain, and protect patients. Therefore nurses are the natural protectors of patient rights. For example Bandman and Bandman (2002, p. 25) argue that: "*patient rights need to be protected; nurses have a natural alliance with their patients*." However even if one were to accept that patient rights need protecting, it is a large leap to move from the position that part of the nursing role is to support and protect patients (presumably in certain situations, for particular reasons and against particular sets of circumstances), to the claim that nurses are therefore the natural protectors of patients in all situations. Bandman and Bandman's claim that nurses "*have a natural alliance with their patients*" also merits some scrutiny. Latimer (2000) provides graphic evidence that this is not in fact the case. On the basis of empirical findings Latimer argues that an important nursing function, as manifest in organisational culture, is to protect the image of modern medicine; even when this is to the detriment of patient care and the exercise of individual patient autonomy and right to self-determination. In a similar vein Conlon (2013) argues that in an effort to maintain the status quo in the unit many nurses do not advocate for adequate pain relief for patients – nor do they consistently administer analgesic medication to ensure optimum pain relief.
2. Doctors do not always behave in a responsible, accountable manner towards patients. Patients need a knowledgeable supporter to intervene on their behalf with medical staff. The nurse, because of the nursing role and relationship with the patient, is the most suitable person to bridge the gap between the doctor's behaviour and the patient's needs. Bandman and Bandman (2002, p. 25–26) state:

    > The health care system of "checks and balances" calls for resources, skills, and abilities aimed at protecting patients' rights that are not always guaranteed or implemented by physicians. Moreover, nurses, who increasingly show evidence of higher education, quite naturally provide a form of effective advocacy in the delivery of increasingly complex nursing care. Evidence of high-quality nursing judgements in medical centres point to a natural advocacy role for such nurses.

In considering this particular argument in relation to the advocacy role of the nurse the following can be said: (a) It is the case that not all doctors behave in a responsible, accountable manner, as many medical scandals in both Ireland and the UK attest - for example Harding Clark (2006), Francis (2010). (b) It is also the case that nurses frequently input / perceive that they input very relevant information regarding a patient's understanding, wishes, home situation and so forth into case discussions and doctors rounds (Tomaschewski-Barlem et al. 2015). However, there are difficulties in moving from an acceptance of points (a) and (b) above to the conclusion that nurses are appropriate patient advocates. The first obvious difficulty is that irresponsible, inappropriate patient care is clearly not the exclusive preserve of medicine – cases such as those reported by the Quality Care Commission (2011) and the Francis Report (Francis 2010) attest to this fact, as does HIQA (2015) within the Irish healthcare context. This suggests that nurses may be no more appropriate to function as patient advocates than doctors, because some nurses, like some doctors, may abuse the power of their role. They may undermine patient rights and provide inappropriate or detrimental care to patients. Therefore if patient rights and the standard of patient care are in danger of being undermined by the professionals providing that care, patients do need advocates. However, it appears that these advocates cannot be reliably found among healthcare professionals involved in the provision of care to the particular patient concerned.

The second difficulty with moving from an acceptance of (a) and (b) above to a conclusion that the nurse is an appropriate patient advocate is as follows: It is the case that some nurses do input into doctors' rounds and case conferences, and such input may be relevant to advocacy. However, currently there is little evidence that all nurses make such an input, or that all nurses do so consistently. In fact there is evidence that some nurses, in some contexts, do not do so at all – even when they feel very strongly that a patient is receiving inappropriate treatment (Barlem et al. 2012).

Such evidence appears to suggest that the foundation for an advocacy function within the nursing role may rest on very shaky ground indeed. Conlon's 2013 work on PRN analgesia administration would support this suggestion. Conlon explores nursing perceptions and practice in the provision of analgesia to children in their care. She found very variable practice and little evidence of child-centred care.

3. A third argument that is frequently offered in support of the advocacy role of the nurse is that nurses are the healthcare professionals with the most sustained contact with patients. They see patients usually over an eight to twelve hour shift, and nurses are with the patients over the 24-hour cycle, for the entire period of the patients' hospitalisation. Nurses are therefore in a much better position than any other healthcare professional to get to know a patient and to come to understand the patient's perspective. This argument does seem to hold some weight in terms of supporting an advocacy role for nurses. Moving from the acute general hospital environment to the context of mental health and community care provision adds further strength to the claims of a legitimate advocacy role for nurses. In the mental health environment patient – practitioner contact, and consequent growth in knowledge of a patient, may extend over months and years.

Such sustained and lengthy patient contact must create the potential for a nurse to develop a real understanding and knowledge of a patient. In the community context, a study examining the role of public health nurses in the Western Health Board region of Ireland Begley et al. (2004) reported the following:

> "several respondents noted that this multiplicity of roles included acting as the client's advocate. One commented that her duties involved:
> …report writing on social issues, as in housing issues, as in overcrowding, as in poor housing, doing battle with environmental health officers, doing battle with the housing section, trying to get extensions for disabled people. (3)
>
> Another noted how she had to fight the cause of travellers to obtain services:
>
> No, there is no social worker that deals with the travellers but, no … in my area I deal with them and they themselves as travellers have specific needs. Many times you are fighting their cause, you are looking for maybe equipment for them, you are advising them where to get extra services, writing to the urban council to get them housing. (17)
>
> This approach to advocacy culminated in the respondent who saw her responsibility as empowerment; she said:
>
> I think that we should be empowering them. I'd prefer to be empowering them and encouraging them to do it for themselves" (20) (Begley et al. 2004, p. 42).

However it is also the case that in the acute physical healthcare sector contact with patients is for much shorter periods of time than those encountered in either community mental health or public health nursing. Nonetheless by the end of one shift a nurse will have had the possibility to gain insights into a patient's perspective that is much less likely to be afforded a member of medical staff. A doctor may spend approximately 30 min "admitting" the patient and perhaps another 10 min involved in patient examination, treatment or consultation. The importance of the nurse's role in patient monitoring, observation, and in knowing the patient and the patient's responses, is well established from the time of Florence Nightingale and is a recurring theme in the nursing literature – for example Scott et al. (2014).

It is also the case that the nurse is the one member of the healthcare team that is likely to see the full patient care picture, with the patient at the centre of that care. Hospital nurses organise the context within which the patient receives and experiences healthcare. Nurses are the practitioners who not only provide nursing care to a patient, but who also witness, facilitate, and support the provision of care and treatment to the patient, from all other practitioners on the healthcare team. However it needs to be recognised that the changing role of the nurse in acute hospital care is likely to impact on this ability to know the patient and thus be an effective patient advocate. Many of our connections with patients resulted from spending time with them providing basic care – feeding and washing patients, for example. Much of this care is now provided by care assistants. In some contexts, such as the Irish acute hospital sector, nursing shift patterns may also mitigate against being an effective patient advocate. A nurse may do three 12–hour shifts in a row and then have a week off duty. With reduced lengths of stay this may mean the nurse who knows the patient best is not around for key meetings, discharge planning, and so forth. This underlines differences between nursing in the acute and community care contexts with regards to the advocacy role of the nurse. Nonetheless the co-ordinating role of the nurse remains an important part of patient care.

Begley et al. argue along similar lines regarding the role of the Public Health Nurse (PHN):

> …the capacity of the PHN to see the 'big picture' due to their extensive knowledge and experience of care in the community is a critical strength of the role… The PHN is often the first professional the patient encounters in the community and they often look to the nurse "to pull it all together" (Begley et al. 2004, p. 94)

This might mean that a nurse, therefore, is in a better position to understand and represent a patient's views than other members of the health care team.

The importance of the co-ordination of care role is confirmed within the Irish acute care context by Scott et al. (2006) in a Delphi study investigating the core elements of nursing practice. This would seem to suggest a particular and unique nursing contribution to patient care, an element of which practising nurses term "advocacy".

Interestingly the elements of this 'advocacy' include both the "normal" and the "nurse theorist sense of advocacy" described by Seedhouse (2000). This would suggest that Seedhouse has drawn too sharp a distinction between these two senses of advocacy. This distinction appears to be alien in the world of clinical practice. What the literature, and some empirical evidence, suggests is that from the perspective of practising nurses patient advocacy is a continuum. A continuum from pleading a case on behalf of a patient to helping a dying person find comfort and meaning in their experience. To use the words of Woodrow (1997, p. 229):

> … advocacy need not be a reactive process in the case of major crises,. . but can be proactive in the case of less sensational quality issues such as:
>
> - Encouraging patient involvement in planning care
> - Giving information to enable informed decision making by patients
> - Removing restrictive visiting times in any institutional settings
> - Avoiding disturbing patients routinely in the early morning.

The first two elements in the list above could, for example, ease the situations for Alice and Mr. S and make their hospital experience less frightening and frustrating.

To return to Paley (1996), advocacy means different things depending on the particular theory driving the particular intervention under consideration. From the perspective of a theory of nursing that focuses on holistic patient care, and sees nurses as organisers of the patient care context, the notion of a patient advocacy role for the nurse seems entirely coherent.

Some Common Arguments against an Advocacy Role for Nurses

One common argument against the advocacy role for nurses is that nurses do not have sufficient power within the healthcare system to advocate for patients. In the context of the hierarchical organisation of the health service nurses, being part of the less powerful levels of the hierarchy, have insufficient power to challenge medical authority. To ask nurses to do so potentially places the nurse in an untenable position where standing up for a patient or for appropriate patient care results in nurses being disciplined, victimised, and ultimately potentially out of work (Negarandeh et al. 2006).

There are however at least two pertinent issues to consider here. If, as I suggest, advocacy should be seen as a continuum then it is not appropriate to assume that advocating for a patient will always or inevitably bring the nurse into conflict with powerful members of the medical staff. Advocating on behalf of a patient may simply mean bringing an issue to the attention of the medical team (this would be helpful to Mr. S in his search for more information on the prescribed medication and available alternatives), at the appropriate moment or in a context that highlights the importance, or relevance, of an issue to the patient involved (as described by Conlon 2013 and Tomaschewski-Barlem et al. 2015). While conflict and the potential for conflict clearly exists between all members of the healthcare team, sometimes in issues of patient care there is strength in focusing on a common "enemy". Bandman and Bandman (2002, p. 24–25) comment on this issue as follows:

> Instead of health professional conflict, there is or ought to be a natural alliance between nurse, patient and physician against ill health and disease. … To advocate for the client's need is to be part of the health team working with others for the health of the patient.

Therefore it seems important not to trivialise the potentially multifaceted needs for advocacy that may face our patients, by describing advocacy in terms of a turf war between nursing and medicine. The fact that attempts at patient advocacy may sometimes degenerate into such a turf war is neither an indication that there are no real advocacy needs from a patient's perspective, nor that nurses may not, at least on occasion, be very effective patient advocates.

Given that patient advocacy may at least occasionally place extreme demands on the nurse, the second issue that deserves attention here is "What does this imply?". Does the reality of these extreme demands mean that nurses should not be asked to advocate for patients? Or, conversely, does the existence of such extreme risks for nurses imply that the registration body for nurses, health service managers and / or society as a whole, should take their corporate responsibility more seriously? Should there be measures that ensure certain protections for nurses who provide appropriate advocacy for patients'- measures that ensure protection from unfair treatment? This latter position seems to be the position evidenced in the Irish and UK health systems (HSE 2011; NHS 2015).

A second argument against an advocacy role for nurses is that patients do not normally choose their nurses, and nurses do not generally choose their patients – they are more likely to be allocated patients. In the legal sense of advocacy the notion of choosing one's advocate is integral to the role. This lack of choice for patients means that nurses cannot be patient advocates in the legal sense of the word.

It is true that a patient generally chooses their general practitioner and it is more a matter of luck or chance what particular nurse a patient ends up with. This is the case whether one is part of a primary nursing system in an acute hospital setting or receiving the care of a community mental health nurse or a public health nurse. The nurse is therefore in some sense "imposed" on the patient, rather than chosen. However this distinction, even if relevant, can only be taken so far. For example in looking for a lawyer, my choice may be restricted by; my ability to pay; to travel to search for a lawyer; geography; the availability of more than one lawyer in a practice; the case load of those lawyers available, and so forth. This also holds true for my choice of general practitioner. Therefore while nurses are "imposed" on patients and GPs and lawyers are "chosen", one's ability to chose is likely to be limited by any number of factors. Also in most systems of organising the delivery of nursing care there is still the possibility for a patient to choose to develop a trusting relationship with one nurse rather than another. The patient may divulge certain relevant information to one nurse rather than another, and seek help and support from one nurse rather than another. This is the case whether the patient finds themselves on a ward with a staff of twenty nurses, or being cared for at home by a mental health home care team.

A third argument against an advocacy role for nurses is that nurses, as part of the system, are by definition part of the problem. Unfortunately there is clear evidence that nurses can indeed be part of the problems that make patient advocacy necessary. Work such as that of Latimer (2000), Francis (2010), Conlon (2013), and HIQA (2015) show this clearly. If this is the case then it would appear that such nurses cannot provide effective advocacy for the patients involved. Recourse to another form of advocacy is required. In some systems lay advocates are employed by the health service to meet this eventuality. In a number of Irish hospitals the Patient Complaints Officer fulfils this role.

However once again it needs to be emphasised, as our two patient case studies indicate, that systems problems are not the only type of problems that patients' encounter within the health service, nor are they the only instances where advocacy is required. Many of the problems encountered by patients are issues that nurses and other healthcare staff could easily help with; by trying to understand the patient context, patient experience, and developing greater insight into the needs of the patient, rather than what the practitioner assumes are those needs. These issues are in many ways at the heart of the practitioner –patient relationship.[2]

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[2] For a more detailed discussion of the nurse-patient relationship please see Chap. 1.

Conclusion

Current health services are complex, multifaceted organisations. Due to the level of complexity and the numerous demands placed on practitioners within the service, it seems to be the case that more than one form of advocacy is likely to be required by patients within our health services. It also seems that nurses, due to their unique organisational, co-ordinating, interconnecting position within the delivery of that health service, can effectively advocate for patients. In certain circumstances the nurse may be the only practitioner with sufficient knowledge of the patient's desires and wishes to effectively advocate for a patient. It follows therefore that nurses should advocate for patients, when it is appropriate that they do so. This argument of course does not support a unique advocacy role for nurses. Many health care workers may have such as role. The important thing is that patients can connect with a caregiver and that that caregiver has the skills, confidence, and authority to advocate if required. It is less about who advocates for the patient and more about making sure it gets done.

Key Learning Points

- The role of the nurse as patient advocate is very well accepted in both nursing practice contexts internationally and in the nursing literature.
- There are reasons, such as increased vulnerability when one is ill and the natural power imbalance in the practitioner-patient relationship, why patients may need an advocate.
- However, in practice, an advocacy role for nurses is not uncontroversial and there are arguments both in favour and against such a role for nurses.
- An analysis of nursing practice and the function of the nurse does support an advocacy role for nurses – but such a role, in the health care context, is not exclusive to nurses.
- The most important thing is that patients should receive the support they need to participate in and understand their care, not who provides such support.

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Ethical Issues at the Beginning of Life

9

Janet Holt

Abstract

This chapter explores the ethical and legal issues faced when caring for pregnant women. A case study involving four women who have used or are contemplating using reproductive technologies forms the basis of the chapter to illustrate and discuss the issues raised. The issue at the heart of the debate is the question of when life begins and what sort of status we should afford to the entity that develops from a fertilised ovum through various stages to be a fully formed baby. Beginning with an exploration of this concept of when life begins and begins to matter, assisted conception, surrogacy and prenatal diagnosis are discussed. This is followed by a consideration of the notion of choosing children including the creation of saviour siblings. The final section of the chapter considers the complex ethical issue of abortion particularly on the grounds of fetal abnormality. Differing views on the moral status of the embryo are explored along with common reasons for justifying abortion. The chapter concludes with a glimpse into the future, with an examination of new and emerging technologies.

Keywords

Assisted conception • Abortion • Prenatal diagnosis • Saviour siblings

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P.A. Scott (ed.), *Key Concepts and Issues in Nursing Ethics*,
DOI 10.1007/978-3-319-49250-6_9

Introduction (Including Case Study)

Over the last 50 years technological advances and new treatments have been developed in the care of pregnant women. There have also been changes in the law to allow abortion under some circumstances, and sophisticated treatments for infertility, all of which give rise to ethical questions focusing on the very essence of human life. Beginning with a discussion of when life begins, this chapter will explore some of the ethical issues in contemporary healthcare including assisted conception, surrogacy, prenatal diagnosis, the creation of saviour siblings, and the controversial subject of abortion. A case study involving four women in different stages of their reproductive lives will be used to illustrate and inform the debate. The chapter concludes with a consideration of new and potentially controversial techniques emerging in reproductive medicine.

Clare, Saadia, Ruth and Liz are friends who were at secondary school together over ten years ago. They now live in different parts of the country, but meet up for a reunion every year. At their most recent meeting, two of the friends are pregnant, Clare with her first child and Saadia with her second. Saadia knows that the baby is a boy who they are going to name Amir. Saadia's first child, Yusuf, now 4 years old, was born with beta thalassaemia, an inherited condition which means that he has to have regular blood transfusions. Saadia explains that she had undergone IVF in this pregnancy to ensure that her baby would be a tissue match for Yusuf. Immediately after birth some blood will be taken from the umbilical cord and the cells in it used to treat Yusuf and hopefully cure his condition.

Clare is in the early stages of her pregnancy, and tells her friends that she is worried about the tests she has recently had to exclude fetal abnormality. Clare has a brother with Down's syndrome and knows how difficult her parents found caring for a disabled child. But she is very uncomfortable with the idea of termination and says she doesn't know what she would do if she was told there was something wrong with her baby. Liz, who has had four children in six years, is adamant that she wouldn't want another child and says that she just couldn't cope. While she understands Clare's views, she says she wouldn't be concerned at all about having a termination and thinks that it is her right as a woman to have this choice.

Ruth tells her friends that she hadn't planned to have any more children, feeling that her family is complete with the two she has. But recently her sister has undergone treatment for breast cancer, and has been advised to freeze some of her eggs as the treatment is likely to affect her fertility. Ruth asks her friends what they think about surrogacy and wonders if she should offer to have a child for her sister.

The women in this scenario face a number of challenges concerning the way in which they view the moral status of the fetus, the use of assisted conception and prenatal diagnosis, the creation of saviour siblings, and the ethical dilemma of abortion. Central to all of these and other ethical problems in reproductive technology is the fundamental question of when life begins; this is where we will begin this exploration.

When Does Life Begin?

There are several different claims about when human life comes into existence. These claims are important as they are relevant to the question of what status should be afforded to the human embryo and ultimately what can be done to it. For some people, life begins at conception, that is, when the sperm fuses with a mature ovum to form the early embryo. In many respect this is the most obvious point to identify as the beginning of life, as the fertilisation of the ovum by the sperm, each containing 23 chromosomes, causes the creation of a new life. For some people this means that the embryo, from the moment of conception, should have the same degree of protection as any other human being.

But fertilisation does not always produce an embryo and on rare occasions (approximately 1 in 700–800 pregnancies per year), the fertilised ovum does not develop normally and while there is a mass of rapidly growing cells called a hydatidiform mole, no embryo develops. As a molar pregnancy is likely to develop into a choriocarcinoma,[1] it is usually removed as soon as a diagnosis has been made. To suggest that the mole should not be removed would be a difficult argument to sustain, firstly because there is no embryo, and secondly, because of the potential dangers of not removing it. We cannot even describe a fertilised ovum as being the beginning of a unique new life, as there is still a possibility of twins being formed from the single fertilised ovum as late as 2 weeks following conception. Nevertheless people holding what are described as Pro-life views, such as members of the Society for the Protection of Unborn Children (SPUC), unequivocally state that life begins at conception because at that point *"a person is genetically complete, unquestionably human, distinct from mother and father, and alive - with the capacity to grow and develop to maturity"* (SPUC 2016).

Before the advent of ultrasound, much significance was placed on the first time a woman felt the fetus move, usually around 16 to 20 weeks. Reference to fetal movements can be found in the Gospel of Luke in the Bible. Luke describes a meeting between Mary, pregnant with Jesus, and Elizabeth who was pregnant with John the Baptist. On hearing Mary's voice, Elizabeth says that "the babe leaped within her womb" (Luke 1:41). It is not surprising that this was associated with the beginning of life as a moving fetus clearly indicated a "live" fetus. In traditional Roman Catholic theology, the first fetal movements had even more significance, in that they indicated the moment when the soul is created in the embryo. Aristotle believed that a male body was formed at 40 days, but that of a female took 90 days to be formed. Thomas Aquinas, a thirteen century theologian developed Aristotle's theory further by proposing that God creates the soul within the embryo at 40 days for males and 90 days for females (Gillon 2001). From this we can conclude that for Aquinas, male fetuses were valuable at an earlier stage than female ones. While a moving fetus is undeniably a "live" fetus, modern ultrasound techniques show fetal movements are present much earlier in pregnancy than when the woman begins to feel them, or than suggested in historical accounts.

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[1] A fast growing cancer in the uterus originating in tissue that would normally form the placenta.

In 1984 an influential committee chaired by Dame Mary Warnock debated the ethical and social implications of infertility treatment and embryo research following the birth of the first 'test tube baby' (DHSS 1984). An important point to emerge was the significance of the primitive streak, that is, the beginning of the individual biological development of the embryo and the last point at which twinning can occur. The primitive streak represents early development of cells that will develop into neural tissue, the very first stages of the nervous system and hence the root of consciousness. As the primitive streak develops on day 15, one of the Committee's recommendations was that embryo research should only be allowed up to 14 days after fertilisation. While ensuring experimentation would only be carried out on embryos before the appearance of any neural tissue, this could be interpreted as meaning that embryos up to this point are seen to be less valuable than those over 14 days.

Even if it is not possible to argue that life definitely begins at conception, and that a new individual is created at that point, it does still seem plausible to recognise the importance of conception. Following this line of argument, we might say that while there is a continuum of human development, the embryo even in the earliest stages has the genetic material of a human and, given the right conditions, will develop into a human being. Therefore, the embryo should be afforded the same rights and protection as any human being. This is called the potentiality argument.

John Harris (1985) points to two problems with this argument. Firstly, the fact that something will become X is not a good reason for treating it now as if it were X. For example, an acorn, given the correct conditions has the potential to grow into an oak tree, but does this mean that should we treat an acorn the same as an oak tree? Or to put it another way, do you think that squashing an acorn is the same as cutting down an oak tree that is a 100 years old? Even using acorns and oak trees as the example still has a moral nuance. We may have more reservations about cutting down an ancient tree without due cause than standing on the acorn accidentally or otherwise. The second problem relates to the ova and sperm individually, as clearly they too have the potential to become human beings. Generally speaking we do not take much care over the fate of "unwanted" ova or sperm. However, following the potentiality argument methods of contraception that destroy ova and/or sperm could be deemed morally wrong, and Roman Catholics have teaching forbidding the use of contraception based upon this argument.

When Does Life Begin to Matter?

The development of the fertilized ovum into an embryo, fetus, and ultimately a baby, can be thought of as a continuum with stages that merge into each other. Therefore, rather than trying to answer the question 'when does life begin' a different approach is to ask 'when does life begin to matter'. We have already seen that the emergence of the primitive streak is a biological event which marks the development of neurological tissues, and the emergence of the sentient being[2] is linked to

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[2] A sentient being is one that can feel pleasure or pain.

this concept. Peter Singer (2012) argues that if a sentient being, human or non-human, can feel pain or distress then it's interests should be given the same consideration as any other human being. So if hurting or destroying sentient beings is considered to be wrong, then sentient beings should not be harmed. However, non-sentient beings cannot be harmed by their destruction as they do not have the capacity to feel pleasure or pain and thus cannot be harmed. Based on sentience, abortion and embryo research are legitimate as long as the embryo cannot feel any pain; as the argument from sentience only prohibits hurting the sentient entity but does not offer absolute protection.

Leaving biological definitions and sentience to one side, a far more complex issue, and one of the most influential philosophical arguments about when life begins to matter, is that of the recognition of self or personhood. The precise meaning is hard to define, but personhood is essentially the things that make us human, or the combination of beliefs, desires, and aspects of personality that make us who we are. From as early as the seventieth century this has been described as a combination of rationality and self-consciousness (Locke 1997). More recently and directly related to abortion and infanticide, Michael Tooley defined the criterion for personhood as an organism that *"possesses the concept of a self as a continuing subject of experiences and other mental states, and believes that it is itself such a continuing entity"* (Tooley 1972, p. 29). So for Tooley, in order to have a claim to a right to life, the person must be able to recognise themselves as the same being over time. Therefore, killing a person is wrong as it removes from the individual something they are able to value, but using this distinction, individuals who cannot value their own existence cannot be wronged by killing as they are not deprived of something they are capable of valuing. While this may be a persuasive argument, a key problem with defining personhood as a combination of rationality and self-consciousness is that fetuses, babies, some adults with learning disabilities, those in a permanent vegetative state, and even some with dementia cannot be classified as persons.[3]

Having explored some of the differing views on when life begins and begins to matter, we will now turn to some of the contemporary uses of reproductive technologies and the ethical questions that face Clare, Saadia, Ruth and Liz. To ensure a tissue match for her son with beta thalassaemia, Saadia has become pregnant using IVF, while Ruth is considering being a surrogate for her sister's baby.

Assisted Conception

Since the birth of Louise Brown, the first 'test tube' baby, in 1978, increasingly sophisticated techniques to assist conception have been developed. Some forms of treatment, such as those that solely use medication, are not usually considered controversial. However other techniques, such as the use of donor sperm and/or ova, IVF, and surrogacy, do raise ethical problems. Opinions on the morality of assisted

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[3] For a detailed introduction to the concept of person and related debates please see Chap. 6.

conception rest on an individual's view of the moral status of the embryo. The idea of creating a life in vitro is considered to be unnatural and, unsurprisingly, those who hold pro-life views are generally opposed to IVF. What lies at the heart of this debate is whether infertility is considered a disease to be treated the same as any other condition. At the very least, infertility is a malfunction of part of the body much in the way that diabetes is. Treatment of diabetes with insulin, like many other medications, may also be considered unnatural; yet we would not consider this to be a sufficient reason to deny someone having insulin. But while infertility might be thought of as a malfunction of the body, unlike diabetes, the treatment is not life-saving. Although infertility is a cause of suffering and misery to those unable to have much wanted children. There is also the added problem that the treatment is concerned with creating embryos, not all of which will be used. Those that are not may be discarded or used in research. Despite some moral objections to the assisted conception process it is widely utilised. The latest figures show that in 2013 49,636 women were treated and 2.2% of all the babies born in the UK in 2012 were as a result of IVF (HFEA 2014a).

In the scenario, Ruth's sister is facing infertility because of her cancer treatment and Ruth wonders if she should offer to have a baby for her. In the UK surrogacy is lawful if, by using IVF, an embryo is created using the ova and sperm of the intended parents. As Ruth's sister will have some of her ova frozen, this is the process they will most likely use. Therefore, Ruth will have the embryo created from her sister and partner's sperm implanted into Ruth's uterus. Surrogacy can also occur when a donated ovum is fertilised with the intended father's sperm, using an embryo created using a donor ovum and sperm, or when the surrogate's ovum is fertilised with the intended father's sperm usually using the more straightforward process of artificial insemination. In the UK surrogacy is regulated by the Surrogacy Arrangements Act 1985 and while a surrogate can be paid reasonable expenses, engaging in a commercial surrogacy arrangement, where the surrogate is paid for the service, is a criminal act (Hoppe and Miola 2014).

While Ruth can be a surrogate for her sister, she would need to consider that not all of the process is legally enforceable. So while Ruth as the person who carries the child will be the birth mother, if she is married her husband will be assumed to be the father. Furthermore, Ruth is entitled to change her mind once the baby is born and not give the child to her sister. Similarly, her sister may decide that she does not want the child after all and Ruth will then have to keep it. At some stage Ruth and her sister will have to decide what the child is going to be told about the manner of his or her conception and all members of the family will need to understand and agree to this. Ruth may develop a strong attachment to the child and still feel it in some way belongs to her, all of which could upset family dynamics. Conversely the bonds that have develop between Ruth, her sister, and the child might strengthen their relationships. So while Ruth and her sister will enter into a form of contract, much of it is based on trust. Keeping the arrangement in the family might help to establish that trust, but the act is one of altruism and not without complications.

Ruth will also have to decide, possibly in conjunction with her sister, if she will undergo screening tests for fetal abnormality and what they will do should the tests show something wrong with the baby. Clare has already undergone a series of tests and is now anxiously waiting for the results. In the next section we consider the ethical problems that women like Clare and Ruth face in undergoing prenatal diagnosis.

Prenatal Diagnosis

All women in Ireland and the UK are offered screening tests in pregnancy, to detect fetal abnormality. These usually take the form of blood tests and ultrasound scans. Thus women are given a choice about the tests they want to have and can, if they wish, refuse to have any tests altogether. Until very recently the blood tests taken to detect fetal abnormalities such as Down’s syndrome were not very accurate, and only gave women a ratio of the likelihood of the fetus being affected. Any woman thought to be at risk was then offered an amniocentesis. This is an invasive procedure where fluid is extracted from the amniotic sac surrounding the fetus and the cells contained within it examined. But now a non-invasive prenatal blood test (NIPT) is available to test for genetic conditions as early as 10 weeks into the pregnancy. These tests are much more accurate and substantially reduce the number of women who need to proceed to amniocentesis with its accompanying risk of miscarriage. In January 2016, the UK National Screening Committee recommended that the test be made available to women in the UK. Research into the benefits and costs published in April 2016 (Chitty et al. 2016) claimed the test to be cost effective and offering improved quality of care and choice for women.

However, offering easier and non-invasive tests does raise ethical issues. Prenatal testing for some women inevitably leads to difficult decisions about what to do if an abnormality is detected. There is usually no treatment for the fetus in utero, and the woman is faced with the choice of continuing with the pregnancy or having an abortion. This is the dilemma facing Clare in the scenario. If Clare is a resident and citizen of England, Scotland or Wales, and told her baby has an abnormality such as Down’s syndrome she would be given a choice to continue or to terminate the pregnancy. Giving women the choice respects autonomy and, assuming Clare has capacity, to do otherwise would be legally and morally indefensible. However, this is a very difficult decision to make and both choices have associated problems. Clare can decide to have an abortion, but evidence shows that while termination of unwanted or unplanned pregnancies are rarely accompanied by psychological and social problems, terminations carried out on the grounds of fetal abnormality are different. These are often planned and wanted pregnancies and typically carried out later in pregnancy, when the termination is more difficult to cope with and obvious to family and friends (Donnai et al. 1981). If Clare decides to continue with the pregnancy she faces an uncertain future having personal experience of how difficult caring for a child with disabilities can be.

It is plausible that women may agree to tests, particularly those that are non-invasive such as blood tests and ultrasound scans, without fully considering the potential outcomes. Norton et al. (2014) identify a discrepancy between women and providers about the nature of prenatal testing. They conclude that while women want assurance that the fetus is developing normally, healthcare professionals usually consider testing as a means to identify abnormalities for which the woman would choose to terminate the pregnancy. So while making a decision to continue with a pregnancy or not is described as a 'choice' it may be one that women like Clare would prefer not to make at all. Perhaps the notion of choice regarding termination is misplaced and would be better considered before any testing takes place. In this way, women could freely enter into the testing process being clear that they not only have a choice about having the tests and, depending on the results, what this may lead to. This is particularly relevant because of the plans to roll out NIPTs to be offered free to all women through the NHS.

For many women the idea of not giving birth to a child with disabilities is a benefit, but others express concerns about prenatal screening programmes being 'seek and destroy' missions and a form of eugenics. Because of its history, eugenics, the practice of genetically improving humans, is generally considered to be a bad thing. Selgelid (2014), however, argues that while prenatal diagnosis in some respects does fit the criteria of eugenics, for those not opposed to abortion on moral grounds, eugenics per se is not necessarily a bad thing. Advocating an approach far removed from the state controlled policies of the past, Selgelid describes an era of new genetics where individuals freely choose to have prenatal diagnosis and act on the information obtained from the tests. A position that he considers to be entirely different to past coercive practices such as state sponsored sterilisation of people with undesirable genetic traits. Nevertheless, despite legislation to ensure equality in our society, there are still concerns that wider use and availability of prenatal genetic testing could make life difficult for people with disabilities. Abortion following prenatal diagnosis has been described as expressing discriminatory attitudes not just about the condition, but also about those who have it (Parens and Asch 2012). Therefore, abortion on the grounds of fetal abnormality could result in fewer people with disabilities being born. Also, those whose birth could have been prevented, by the use of prenatal diagnosis and selective abortion, could be considered less valuable and more vulnerable to prejudice and discrimination.

Saviour Siblings

Where there is a known genetic or inherited condition, an alternative to prenatal testing and termination is to offer the woman in-vitro fertilisation (IVF) with preimplantation genetic testing (PGD) so that only healthy embryos are implanted into the uterus. Saadia has undergone this procedure to ensure that her second child will not only be free of the inherited disease but will also be a tissue match for Yusuf. This is known as the creation of a saviour sibling. In the UK, the Human Fertilisation and Embryology Act 2008 allows saviour sibling selection as long as the recipient has a serious medical condition which can be treated by cord blood, bone marrow or other tissues (HFEA 2014b).

The advantage for Saadia is that no harm will be done to her baby and the cord blood containing stem cells may be the only hope of a cure for Yusuf. A further advantage is that the embryo selection takes place prior to implantation. The cells for testing are removed 2–3 days after conception, so the embryo is in a very early stage of development. As discussed above, for some people, the embryo at this stage has less value and therefore this process is morally more preferable than an abortion at a later stage in the pregnancy. Of course this is not the case for those who believe that life begins at conception, and such individuals would raise objections to this process seeing it as morally no different to an abortion.

Saadia has been fortunate in that an embryo has been successfully created that is a tissue match for Yusuf. But this does not always happen, and there have been cases where despite repeated attempts, a tissue match has not been achieved. There is also the problem of what to tell Amir about the manner and reason for his birth. Opponents of saviour siblings argue that the process reduces children to a commodity and thus not considered as ends in themselves.[4] Amir may feel that his parents did not want him for his own sake, but given the lengths his parents went to, this could suggest they are committed parents. Therefore there seems no reason to suspect that Amir will not be loved as much as Yusuf. Indeed it could be argued that, as he has been so instrumental in the treatment of his brother, he may feel particularly valuable and loved. But there is the possibility that the treatment does not work and that Amir is unable to save Yusuf. Or that he feels pressurised into further and more complex donations such as bone marrow at a later date which could cause psychological harm. To date there are no published findings of the psychological impact of being a saviour sibling so we can only speculate, but it should be noted that to object to saviour siblings on the grounds of potential psychological harm is a different argument from the pro-life objection to the artificial creation and section of embryos.

Choosing Children

One of the problems in allowing preimplantation genetic testing (PGD) is the concern that it will not stay restricted to avoiding disease, but lead to allowing individuals to choose other characteristics of their child such as the gender, IQ, or hair colour. With the mapping of the human genome, in the future it may be possible to test an embryo for a number of traits and characteristics that we could select to enhance our potential children. Savulescu (2001) for example draws no distinction between treatment for disease and enhancement and argues that if one is morally permissible then so the other should be. Savulescu develops his argument further to say that in the future if such a thing was possible, genetics tests should be used to only select children expected to have the best life possible which may include a high IQ, an aptitude to play a musical instrument, or achieve sporting prowess. However,

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[4] The requirement to consider persons as” ends in themselves”, as fundamental to the principle of respect for persons, is an important element of Kantian ethics. Please see Chap. 2 for a full discussion of this idea.

giving people the freedom to choose their children in this way could lead to further ethical problems. For example, what if a couple decide they wanted to deliberately create a child with a disability as happened in the United States in 1996. In this case a deaf lesbian couple wanted to have deaf child so selected a congenitally deaf man as a sperm donor to maximise their chances of this occurring (Wilkinson 2010). Here, the couple took matters into their own hands and achieved the pregnancy without using health services. But suppose a couple asked health providers to do this using IVF and PGD. In order to respect their freedom of choice, would health professionals have to comply with their wishes? Of course it would be possible to enact legislation to prevent unrestrained choices, but even within the constraints of the current techniques, individuals do not have absolute freedom. For example, it is possible to test for sex, but individuals using IVF and PGD are not allowed to select an embryo just on sex alone.

There are a number of objections to the practice of choosing children, not least of which are the inequalities that would potentially occur in society. Children could be created who would have an unfair advantage over others. Also, in a publicly funded healthcare system, it is unlikely that all individuals would be able to access what would undoubtedly be expensive procedures. Therefore, only people with the ability to pay may be able to choose their children, creating an elite and potentially entirely different species; with the children of the poor unable to compete with the enhanced children of the rich (Bostrom 2012). While we can only speculate what the consequences of improvements in scientific techniques might be, we can be sure that that this will give rise to many ethical problems in the future.

The process of IVF and PGD that Saadia has undergone has resulted in a positive outcome creating a fetus with a tissue match for Yusuf. But for Clare and Ruth the situation could be very different. Should the tests indicate some form of fetal abnormity they will be faced with the difficult choice of either continuing with the pregnancy and possibly giving birth to a baby with disabilities or ending the pregnancy with an induced abortion.

Abortion

One of the most profound and divisive ethical dilemmas is that of abortion. Abortion is governed by different legislation across the four countries of the UK; in England, Scotland, and Wales, abortion is a criminal act unless carried out under the grounds of the Abortion Act 1967 (amended by the Human Fertilisation and Embryology Act 1990) (Hoppe and Miola 2014). It is important to consider abortion in this way as in England, Scotland, and Wales abortion is not available to women on demand. Termination of a pregnancy is lawful when there is substantial risk of a child being born with physical or mental abnormality, and while for the other clauses there is a time limit of 24 weeks gestation, in cases of fetal abnormity there is no time limit (Hoppe and Miola 2014). The legislation does not extend to Northern Ireland, where abortion is only permissible if a woman's life is at risk or where there is a risk of a serious and adverse effect on her physical or mental health. Abortion is illegal in the

Republic of Ireland, except where the pregnancy presents a real and substantial risk to the life of the mother; including the risk of suicide.

Notwithstanding the law, moral opinion on abortion is sharply divided with opposing views described as pro-life and pro-choice. In a nationally representative sample of members of the general public, there are likely to be few people who believe that abortion should never be carried out in any circumstance or that it should be freely available on demand at any stage of pregnancy. But there are likely many with more nuanced views. For example, an individual may consider themselves to be largely pro-life, but agree that abortion should be allowed in cases of rape, or if there is fetal abnormality. Others may lean more towards a pro-choice stance, but feel it important that there should be an upper time limit in pregnancy, after which it should not be allowed. Essentially the foundation for the opinions lie in the debate on the moral status of the embryo and fetus discussed at the beginning of the chapter; those who believe that life begins at conception generally oppose abortion at any point in the pregnancy. Holding a more nuanced view of abortion can however be very complicated. If for example an individual believes that life begins at conception, they would need to be able to argue why the manner of conception, i.e. rape, is relevant, and can be used to justify killing the fetus. With modern visualisation techniques the appearance and movement of embryos and fetuses can be easily shown and there can be no doubt that abortion does mean killing the entity. However, the crucial issue for those who agree with abortion is being able to justify on moral grounds that it is the more preferable course of action.

Some arguments for and against abortion are rights-based with the woman's right to choose in opposition to the fetus's claim to a right to life. The arguments here focus on moral rights, as in law a fetus is not afforded any rights while still in utero. In the scenario Liz shows no reservations about abortion, and says she believes it is her right as a woman to have the choice. Liz may believe that the fetus isn't an independent entity and simply part of the woman's body and therefore she has the right to make any decisions about what happens to it. This is the line taken in a famous paper *In Defense of Abortion*, published in 1971 by Judith Jarvis Thomson. Through a series of thought experiments Thompson asks the reader to imagine waking up to find that a famous violinist has been plugged into your kidneys for 9 months life support (Thompson 1971). Thompson concludes that the fetus's right to life does not override a pregnant woman's right to control her own body and thus, abortion is permissible.

Clare on the other hand is apprehensive about the thought of abortion, and even though she recognises that the fetus does not have legal rights, she feels that it is a gradually developing entity and can't distinguish between one stage of its development and the next. Clare thinks of the fetus she is carrying already in terms of being a baby, with the same moral status and right to protection as herself. Although her situation is complicated by the results of the prenatal diagnostic tests, the heart of the matter is still the same. If Clare firmly believes that a fetus has a right to life irrespective of any disabilities, she is unlikely to change her mind about this should the tests prove to be positive. This is the root of the complex problem of abortion where individuals disagree on whether abortion is a matter of personal choice for a woman, or, that a fetus, as a potential person, has the right to life and should not be killed in any (or at least in very few, carefully defined) circumstances. Despite a vast philosophical, theological and clinical literature on the subject, it seems impossible that a definitive solution will ever be found to satisfy both the supporters and opponents of abortion.

The Future

This is a fast moving area with scientists and clinicians working on new and improved techniques such as NIPTs and gene editing on early embryos. This technique, approved by the HFEA in February 2016, has the aim of preventing miscarriage and increasing IVF success though greater understanding of early embryo development. Cases of post-menopausal women becoming pregnant through IVF, while rare, are reported in women as old as 72 (Marszal 2016), while the HFEA reports an increasing trend in women freezing their ova to delay parenthood for non-medical reasons (HFEA 2014a). In 2016, the UK became the first country to allow so called three-person IVF for women with mitochondrial disease. The technique allows healthy mitochondria from a woman donor to be combined with the DNA of the parents. The subsequent new genetic material will be passed on through future generations. There are also instances of controversial legal decisions regarding assisted conception. One example is the case decided in July 2016 involving a 60 year old woman being given permission to use IVF in an attempt to become pregnant, using the ova her daughter had frozen before her death from bowel cancer (BBC 2016). Ethical and legal controversy surrounds each of these examples and similar to the issues discussed above, some will argue that research resulting in new methods, particularly with the possibility of treatment, is positive and morally justifiable. But for others interference with what may be considered the essence of life itself will remain morally wrong.

Conclusion

Overall, the use of reproductive technologies has laudable aims to either help those unable to do so to have children, to create children free from disease, disability, or with a tissue match to treat their sick siblings, and to offer women the choice to continue with or terminate a pregnancy. However, as has been shown in the discussion, there are a myriad of ethical problems that arise from such technologies, accompanied by a diverse range of opinions on the morality of their use. What is at the heart of this debate is the fundamental question of when life begins and what sort of status we should afford to the entity that develops from a fertilised ovum, through the embryonic and fetal stages, to a fully-formed baby. Modern visualisation techniques that show this development, particularly at the very earliest stages, bring detailed images where there can be no doubt about the entity as a living being with human characteristics. All of which adds to the dilemma and complexity of the ethical problems faced by women, such as those in the scenario above. There are no easy answers to these problems.

National bodies, such as the HFEA, and the law can be used to enact legislation to govern the use of procedures or address cases bought before the courts, but this will only result in legal responses and practical solutions leaving the central ethical issues unanswered.

Key Learning Points

- There are differing claims about when life begins and when life begins to matter.
- An argument based on sentience permits early abortions and embryo research as the embryo is not hurt.
- Defining personhood as a combination of rationality and self-consciousness has negative implications for individuals who lack capacity.
- Surrogacy is lawful in the UK when the ova and sperm of the intended parents are used, and when the sperm or ova of a donor is used.
- Parents are not allowed by the HFEA to choose the characteristics of their children, but saviour siblings can be created where there is an inherited disease in the family.
- Arguments for and against abortion demonstrate conflict between a woman's right to choose what happens to her body and the fetus's right to protection from harm.

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Ethical Issues at the End of Life

10

Janet Holt

Abstract

This chapter explores the ethical, legal and professional issues that healthcare professionals face when caring for individuals at the end of life. Contemporary guidance will be drawn upon along with an evolving case study and legal judgments to illustrate and discuss the issues raised. Beginning with an exploration of the concept of the good death and the role of palliative care in facilitating a good death, the process of advance care planning and making advanced decisions is discussed. This is followed by a consideration of the withdrawal of treatment and draws on English and Irish cases to illustrate the legal and ethical aspects of futile treatment. The classification of artificially administered nutrition and hydration and the controversy surrounding the use of the Liverpool Care Pathway are also considered. The final sections of the chapter consider the difficult subject of assisted dying, suicide and physician assisted suicide. The discussion is informed by cases in the English and Irish Courts and the attempts to change legislation in the UK. Euthanasia, arguably the most controversial aspect of assisted dying, is examined. Insight from countries such as The Netherlands, where active voluntary euthanasia is lawful, informs the debate.

Keywords

Good death • Palliative care • Withdrawing treatment • Assisted dying • Euthanasia

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P.A. Scott (ed.), *Key Concepts and Issues in Nursing Ethics*,
DOI 10.1007/978-3-319-49250-6_10

Introduction

The care of the dying person is a fundamental and important part of nursing in critical, acute and continuing care as well as in community, hospital, and other institutions settings. While death and the process of dying are of importance to everyone, healthcare professionals face particular challenges in ensuring that high quality care is delivered in accordance with the patients' wishes, and in their best interests. Some of these challenges are of a practical nature, but others pose significant ethical dilemmas and problems for practitioners striving to do the best for their patients while being mindful of their legal and professional duties. Beginning with an examination of the concept of the good death, this chapter explores the ethical issues of withdrawing treatment, including nutrition and hydration, assisted suicide, physician assisted suicide and euthanasia. Contemporary guidance will be drawn upon along with an evolving case study and legal judgments to illustrate and discuss the issues raised.

The Concept of a Good Death (Including Case Study)

While death may be an event, dying is a process which due to technological advances allows patients to be resuscitated, given new treatments and kept alive using artificial means. In some instances, instead of asking 'can we treat the patient?' a more appropriate question may be 'should we treat the patient?' The concept of the good death has been a matter of debate for centuries. For example, discussion of the subject can be found in ancient writings such as Plato's Dialogues from the 5th century BC. In the Phaedo for example, Plato recounts the 'good death' of Socrates who having been convicted of impiety and corruption of the young, chooses to die by taking hemlock rather than escape his prison cell (Plato 1969). For some the idea of a swift and relatively pain free death, such as that resulting from a catastrophic brain injury, might be considered a good death; while for others, a more protracted process that gives time for the person to see friends and relatives, say good bye or 'put their house in order' is more preferable. The quest for a universal definition of a good death therefore may seem futile, and instead should perhaps be recognised as dependent on individual preferences and culturally determined (Goldsteen et al. 2006).

Towards the end of life, many individuals receive palliative care, which is defined by the World Health Organisation (2002, p. 84) as '*an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual*'. The United Kingdom (UK) is recognised as a leader in the development of palliative care as a speciality particularly through the work of Dame Cecily Saunders and the introduction of the hospice movement in 1967. There are also a number of policy and guidance documents specifically addressing end of life care. Two examples are the National

Institute for Health and Care Excellence (NICE) quality standard *End of Life Care for Adults* (NICE 2011), comprising of 16 quality statements to ensure that the best care can be offered to individuals through the NHS, and *The end of life care strategy: New ambitions* (National Council for Palliative Care 2014). While patients may prefer to die in their own homes or in a hospice, opportunities for exercising choice regarding the place of death is limited. In England for example, around half of all deaths occur in hospital (Office for National Statistics 2015) where care may not always be given by palliative care specialists. It is therefore possible that some patients may not receive optimum care, an issue highlighted with the adverse publicity surrounding the use of the Liverpool Care Pathway. This will be discussed later in the chapter. A literature review by Cox et al. (2013) exploring public attitudes to death and dying in the UK, found that individuals' views of the quality of care across different settings were based on the participants' experiences of death of family members, friends and work colleagues. Thus personal experiences can be influential in forming views regarding the quality of care available.

While there have been clear improvements in end of life care there are still inequalities in access to good quality care and support (Leadership Alliance for the Care of Dying People, 2014). This is further exacerbated, in the UK for example, by the complex funding arrangements for end of life care which is only part-funded through the NHS and a substantial amount provided through voluntary sector organisations. Ensuring patients have a choice regarding their place of death as well as access to expert care, irrespective of the place of death, according to policy documents is a key priority in the UK. However, this means that sufficient resources need to be provided to support families and healthcare professionals to put this into practice. The following short case study may help us identify and work through some of the relevant issues here.

Susan is a 58 year old single woman with end-stage ovarian cancer. She lives on her own but has a 30-year-old son Peter who lives 200 miles away, and a 35 year old daughter Clare who lives with her family in Australia. Susan understands her diagnosis and knows that she is expected to die in a few months. She would prefer to be at home, but cannot rely on her children to support her. Having been brought up in the Roman Catholic faith, Susan no longer has any religious beliefs and describes herself as agnostic. Susan values her independence and until recently has been very active in her local community. She has served as a Town Councillor, and as a School Governor and volunteers in the local food bank. Through these activities Susan has enjoyed a good social life and developed a wide group of friends.

Susan's situation is complicated by the fact that she lives on her own and neither of her children are in a positon to help to care for her in her own home. She would therefore need support from community nursing services, and possibly organisations such as Marie Curie which she may be fortunate enough to access. But in a publicly funded health system with competing priorities, despite the best intentions, the goal of high quality care in a place of the patient's choice may well remain aspirational.

Advance Care Planning

Everyone receiving treatment and care from healthcare professionals is entitled to decide what should and what should not happen to them and individuals should expect to have the decisions they make respected. The ethical justification for this is explained by the principle of autonomy. Being free to make autonomous decisions is a key principle in ethics and underpins legally valid consent. However, to exercise an autonomous decision a person must be able to understand the choices available, be free from any controlling influences and make the decision based on accurate information.[1] Under the terms of the Mental Capacity Act 2005 (DoH 2005), capacity is assumed, and incapacity needs to be proven through the use of tests for competence (Pattinson 2011). The Mental Capacity Act came into force in England and Wales in 2007, and provides a framework for decision-making for those no longer able to do this themselves. The remit of the Act is far reaching, but the underlying principles are particularly relevant when caring for people at the end of life. For example, a person should not be treated as lacking capacity simply because they make what is thought to be an unwise decision. People are allowed lawfully to refuse treatment or procedures, in what may seem to others to be an irrational decision. An example of this would be a Jehovah's Witness refusing a lifesaving blood transfusion. While preferring to die rather than have a relatively simple procedure may seem irrational to someone who does not share that faith, as long as the person has capacity and their decision is unquestionably autonomous, then they have both an ethical and legal right to have their decision respected.

The link between autonomy and capacity is important, as it is only by having capacity that a person can exercise an autonomous decision, which consequently places others under an obligation to respect the person's freedom of choice. At this stage in her illness, Susan has capacity and as death is foreseen, she has the opportunity to make some plans about her preferences. For example, she could prepare an advance statement; a written statement that sets out a person's preferences, wishes, beliefs and values regarding their care. Such a statement can be written by any person at any time. And while not legally binding it is designed to ensure any preferences can be recorded, so that should capacity be lost in the future the advance statement could help others, such as Susan's family, in making decisions on her behalf. In the statement Susan could let her family know her preferences about where she would like to die, who she would like to be present, or that she definitely would or would not like to be visited by a priest.

The advance statement is different to an advance decision. An advanced decision is a means by which a person may make decisions about the treatment they would not like to receive, should they lose capacity and be unable to communicate their wishes. Typically, this would include life sustaining treatments such as mechanical ventilation or cardio pulmonary resuscitation (CPR). Advance decisions are sometimes know by other terms such as an advance directive, advance decision to refuse treatment, or living wills. Such advance decisions are legally binding in

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[1] See Chap. 7 for a discussion of the concept and principle of autonomy.

England and Wales under the terms of the Mental Capacity Act (MCA) 2005 (DoH 2005). The MCA also makes provision for proxy decision making through lasting powers of attorney (LPA). This means that a patient can appoint someone of their choice to make treatment decisions they consider to be in their best interests once they lose capacity (Pattinson 2011). There are a number of conditions that have to be met for an LPA to be lawful but even if these are met, it does not mean that they are without problems in practice.

Suppose that Susan, towards the beginning of her illness, made an advance decision that she did not want to have CPR. Later on as Susan's condition starts to deteriorate, Clare her daughter returns from Australia and finds out about the advance decision. Clare is very unhappy about this and tells the health professionals caring for her mother, that she wants everything possible done for her. If Susan still has capacity she will of course be able to explain her decision to Clare herself, and it is recommended that family members or carers be involved in or at least be aware of advance decisions. But if Susan is no longer able to communicate, then it will be up to the health professionals to explain. If Susan has made a fully autonomous decision about the CPR, then there can be no ethical justification to override her wishes just to appease her daughter. This will undoubtedly result in a difficult conversation between the health professionals and Clare, but this is more an issue of effective communication skills rather than one of ethics. Hence in England and Wales an advance decision for refusal of treatment, if valid and applicable, is considered to have the same force in law as if Susan was making the statement contemporaneously.

Withdrawing Treatment

There are situations when rather than making a decision to refuse treatment, the patient themselves insists on being treated against the advice of the health professionals. The patient may understand that there is little chance of success, but decide they still want to receive treatment. For example, suppose that Susan decides that she wanted to continue with her cancer treatment against medical advice because she wants to stay alive until Clare and her family were able to travel from Australia. Even if she understands there are no guarantees that this will happen if the treatment continues, she thinks it's worth the risk. If Susan's autonomous wish is to be respected, then the treatment should continue, but this could be an ethical problem for the health professionals treating Susan, if they believe that the treatment will be of no benefit and not in Susan's best interests. If respecting the patient's autonomy is the best way in which Susan's best interests are protected, then ethically, giving the treatment is justified. But there may be other competing interests or demands such as appropriate utilisation of resources and practising according to best evidence that also need to be taken into consideration. In a publicly funded healthcare system, it is important to ensure that best use is made of the resources available and NICE provides national guidance and advice to improve health care with resources that make best use of available evidence.

The aim of palliative care is to achieve the best quality of life for patients and their families, through the process of diagnosis, treatment and cure or, if there can be no cure, through the continuing illness (National Council for Palliative Care 2015). Administering treatment that is both costly and ineffective cannot be of benefit on an individual level for a patient like Susan, nor does it demonstrate good use of resources for society as a whole. While there may be justification for the withdrawal of medical treatment towards the end of life, there is some disagreement regarding what actually constitutes medical treatment and whether the administration of nutrition and hydration falls within the scope of this definition. A legal interpretation of nutrition and hydration can be found in Airedale NHS Trust v Bland. Tony Bland was a young man severely injured in the Hillsborough football disaster in 1989. He was left in a permanent vegetative state with no hope of recovery and although breathing spontaneously, was fed through a naso-gastric tube. Mr. Bland's parents and treating physician believed that the withdrawal of treatment was in his best interest and so applied to the Court for permission to withdraw all treatment including artificially administered nutrition and hydration. Following a lengthy court case, in 1993, five Law Lords ruled that the artificial hydration and nutrition could lawfully be removed. The Law Lords did not draw a distinction between the provision of nutrition and hydration by artificial means and medical treatment, and consequently held that tube feeding was part of the regime of treatment and care (Pattinson 2011).

In Ireland a similar case, Re a Ward of Court, was heard in the Supreme Court in 1995. The case concerned a woman described as being in a near persistent vegetative state for over 23 years. She had experienced three cardiac arrests while under anaesthetic for minor gynaecological surgery in 1972 and suffered brain damage from which she did not recover. Consequently the woman was unable to communicate, move or swallow and was fed initially by a naso-gastric tube and later via a gastrostomy. The Ward's family asked the court to have the gastrostomy tube removed, but the hospital where she was being cared for objected to discontinuing feeding which they saw as a means of hastening death. The Ward received excellent nursing care, any infections were treated with antibiotics and the nurses described in court the special relationship that had developed between them and the Ward. However, The Supreme Court did rule in favour of discontinuing feeding considering that as the woman lacked capacity, the decision should be made on the basis of best interests. Similar to, and possibly influenced by, the Bland case the Court considered the administration of nutrition and hydration through the gastrostomy tube to be medical treatment. As the treatment was of no net benefit to the Ward, it could be lawfully withdrawn (Dooley and McCarthy 2005).

Therefore, as seen in both of these cases, nutrition and hydration administered by artificial means are classed in law as medical treatment that can in some circumstances be withdrawn. But this classification of feeding as medical treatment is not without its critics and for some, food and fluids constitute ordinary care that should not be withdrawn. In a study where 51 individuals with experience of relatives in either a vegetative or minimally conscious state were interviewed, Kitzinger and Kitzinger (2015) found that even when the respondents thought their relatives would no longer want to be alive, they were '*horrified by the idea of causing death by starvation and dehydration*' (p. 157). Some even thought that administering a lethal injection would be more humane and dignified than death by neglect.

The provision of nutrition and hydration is usually considered to be a fundamental aspect of nursing care, but while nutrition and hydration are necessary for life, the evidence that they are also a requirement for a comfortable death is less clear cut. An important distinction needs to be drawn here between the legality of withdrawing fluids and nutrition and a requirement to do so. If discontinuing fluid and nutrition through clinically assisted means is not considered by all involved in their care, including the patient themselves, as being in the patient's best interests, then there is both a legal and ethical justification to support their removal. However, this does not mean that it has to be done. The guidance from the General Medical Council (2013) specifically addresses this point, recommending that practitioners have dialogue with the patient and those important to them, consider their views and explain the benefits, risk and burdens of providing fluids and/or nutrition on an individual basis. Nevertheless, the removal of clinically assisted nutrition and hydration remain controversial, and as noted by Szawarski and Kakar (2012) likely to be defined by those opposed to assisted dying as a form of killing or at least as a pragmatic but inhumane practice.

Sometimes, the appropriate course of action will be to withdraw or withhold treatment including fluids or nutrition if there appears to be no net benefit to the patient. But it may be questioned whether it is possible to be objective about the futility of treatment. Such judgements may be value laden with patients, relatives and health professionals not necessarily sharing a common understanding of the concept of futility. So while judgements about what is in a patient's best interests are made from the patient's perspective, judgements made with reference to futility inherently assume there is an objective standard for determining benefits and burdens. But this is not the case due to differences not only in values but also in the probabilities of clinical outcomes. As noted by Wilson and Savulescu (2011), even if a treatment is judged futile by healthcare professionals because the chances of recovery are very small, such as 0.5%, some patients would still think this was a chance worth taking if the alternative is death.

Withdrawing treatment has recently been a subject of debate with the controversy surrounding the Liverpool Care Pathway (LCP). Developed in the 1990s, the LCP was based on end of life care developed in hospices and intended as a mechanism to share good practice to other palliative care settings. Hence, it was considered to be the gold standard in end of life care. However, following a series of complaints from family members about inappropriate use of the LCP, an independent review concluded that while there were examples of good use, in a number of cases, the LCP had become a generic protocol, often used without recognition of the individualised care needs of patients - resulting in a tick box exercise (Neuberger 2013). One of the key problems with the implementation of the LCP was a failure to accurately recognise the point at which some patients approached the last few days or hours of their lives, with the implication that the care prescribed by the LCP was commenced at too early a point in the process. This led to accusations of treatment, including fluids and nutrition, being withdrawn too early, in addition to accusations of an over use of sedative medication. Subsequently, the Leadership Alliance for the Care of Dying People, a coalition of 21 national organisations with an interest in end of life care, took forward the recommendations of the Neuberger review and published new guidance in *'One Chance to Get it Right'*. This document details five priorities and focuses on individualised care and good communication between the patient, those that are important to them and healthcare professions in making decisions at the end of life (Leadership Alliance for the Care of Dying People 2014). However, the problems with the LCP occurred because of the inability of some healthcare professions to accurately assess how close to death patients were. This resulted in commencing a regime of care too soon with insufficient provision for individualised care or room for adjustments to be made to that care. It was not a failure of the pathway itself. Therefore, what is crucially important is a commitment, at the highest level, to provide resources to ensure comprehensive education and training for practitioners in implementing the new guidelines, particularly for those not involved in specialist palliative care services such as hospices.

While across all four nations of the UK, there is evidence of the recognition of the importance of palliative care services in the reports and recommendations produced, there is wide variation in state-funding to palliative care services. A substantial amount of care is provided through charitable organisations. By definition this gives rise to ethical issues of disparity and inequality in care provision. Susan therefore may be fortunate enough to live in an area with sufficient funding for palliative care to allow her to die at home supported by community services. Alternatively, she may not, and the burden of care will fall upon her family. If they are unable to provide this, Susan may be faced with no alternative than to receive institutionalised care for example, in a nursing home. Hence the ethical problem that arises is not necessarily one of recognition of individualised care in accordance with the patient's wishes. The ethical problem may be one of implementation and appropriate resource allocation in putting recommendations into effective practice to ensure the provision of individualised care.

Assisted Dying: Suicide and Physician Assisted Suicide

Let us develop the scenario regarding Susan and her illness a little further.

As Susan's cancer progresses, she feels pessimistic about being able to die at home and is worried about needing institutional care. She is less worried about pain or the other symptoms she is experiencing as these are largely under control. What is concerning her is the thought of losing her independence and having to be cared for by nurses for fundamental needs. Susan discusses the possibility of taking her own life with her son Peter and asks him if he would be willing to help her take some medication that will result in her death.

While choice is important, autonomy cannot be considered to be an absolute ethical principle that will take precedence in every case. A person's autonomous choice can be legitimately constrained by the rights of others, as demonstrated in the assisted dying debate. One of the key issues in discussions about assisted dying is confusion in the way that the terms are used. Assisted dying is when a terminally ill person, with capacity, obtains assistance from a third party to help them die. If the assisting person is a doctor, then this is described as physician assisted dying. Under the terms of the Suicide Act 1961 in England and Wales, a legal right to suicide is recognised. However, assisting someone to take their life by aiding, abetting, counselling, or procuring the suicide of another, is an offence and therefore unlawful in the UK (Pattinson 2011). So while Susan can take her own life, her doctor cannot lawfully prescribe medication for her nor can someone lawfully administer medication to her with the intent of aiding her suicide.

Suppose that Peter understands the choice Susan has made and recognises this as a rational, autonomous decision. This does not necessarily mean that he is obliged to respect her wishes and assist her suicide. Susan may have a well thought out plan upon which she wants to act, but in doing so she is asking Peter to act unlawfully and he too must make an autonomous decision. Of course he may agree to do this and accept the consequences of his actions or he may choose not to. Whatever course of action he chooses should be made on the basis of his own autonomous decision not simply because he feels obliged to act according to his mother's wishes. So rather than being an absolute principle, respecting autonomy is described as a prima facie principle. That is one that must be fulfilled unless it conflicts with an equal or stronger claim. Even if he agrees with his mother's decision in principle, Peter might consider the need to keep within the law a stronger claim than Susan's claim to have her autonomy respected.

Physician Assisted Suicide

There have been a number of so called 'right to die' cases brought before the courts in the UK such as that of Tony Bland, Dianne Pretty and more recently the case of Tony Nicklinson, a 58 year old man suffering from locked-in syndrome and paralysed from the neck down following a stroke in 2005.

In 2012, Mr. Nicklinson's case to allow doctors to end his life without fear of prosecution was rejected by the High Court. The case was not considered to be one of assisted suicide as Mr. Nicklinson would have been unable to take lethal drugs, even if they were prepared by someone else. Lord Justice Toulson stated that a decision to allow the case would have far-reaching consequences and that to carry out Mr. Nicklinson's request meant that the court would be making a major change in the law. He added that "It is not for the court to decide whether the law about assisted dying should be changed and, if so, what safeguards should be put in place. Under our system of government these are matters for Parliament to decide" (R (Nicklinson) v Ministry of Justice 2012). Mr. Nicklinson subsequently refused food and fluids and died of pneumonia 2 weeks after the judgment. While undoubtedly a correct legal judgement, authors such as Savulescu (2014) have questioned the ethics of this course of action suggesting that if someone in Tony Nicklinson's position has a right to refuse to eat then he also should be able to exercise a right to die by quickly and painlessly being relieved of his suffering.

The question of rights was also an issue in a recent case brought before the Supreme Court in Ireland (Marie Fleming v. Ireland, Attorney General and the Director of Public Prosecutions 2013). Marie Fleming, a woman with multiple sclerosis, sought permission for her partner to assist her to die at a time of her choice without fear of prosecution. Ms. Fleming claimed that not allowing assistance with her suicide breached her constitutional rights. However, echoing the judgement in the Dianne Pretty Case in the UK, the Supreme Court did not agree and found that there was no constitutional right to die or be assisted to do so.

There have been attempts to bring about a change in law to allow assisted dying in different forms, the most recent being Lord Falconer's Assisted Dying Bill that received two hearings in the House of Lords in 2014 but ran out of time before the end of the parliamentary session. A very similar private members bill was subsequently brought before the House of Commons in September 2015. This bill proposed that a terminally ill person with less than 6 months to live would be able to ask a doctor for help in ending their life. Conditions included confirmation of capacity by a High Court Judge and a written declaration from the patient signed by two doctors. However, MPs overwhelmingly rejected the proposal by 330 votes to 118 (Dyer 2015). A similar bill brought before the Scottish Parliament in 2015 was also unsuccessful. However, in contrast to the situation in the UK, the Canadian Senate passed a bill in June 2016 allowing physician-assisted death for people deemed to be incurably ill (BBC 2016).

Assisted Dying: Dignitas

The defeat of the Assisted Dying Bills in England and Scotland means that it is unlikely that further attempts will be made to bring about changes to the law in the near future. However, another option that is open to people determined to end their lives is to use the services of Dignitas. This Swiss based organisation describes itself as a not-for-profit society that advocates, educates and supports improving care and choice at the end of life. Unlike the UK, the law governing suicide is less strict in Switzerland, where only people who personally gain from assisting a suicide are liable to prosecution and doctors are allowed in some circumstances to provide assistance when patients are terminally ill. Recent research using the database of the Institute of Legal Medicine in Zurich into the prevalence of people travelling to Switzerland found that between 2008 and 2012, 607 people who were not resident in Switzerland had been helped by Dignitas, 126 of whom were from the UK. People with neurological conditions accounted for almost half of the cases with cancer and rheumatic diseases being the next most common conditions. Recent media reports suggest that figure is now over 300 and that one person each fortnight travels from the UK to use the service (Doward 2015).

Let us develop our scenario with Susan and her progressive illness a step further.

Peter has said he won't help Susan take her own life, but she has found out about Dignitas and thinks that perhaps ending her life this way at the time of her choosing may be more preferable. But she is reluctant to travel alone and would like Peter and Clare to be with her when she dies. So she asks them both to accompany her to Zurich.

The Suicide Act 1995 prohibits aiding and abetting suicide (Pattinson 2011), but what of the legal status of relatives or friends accompanying someone to use services of Dignitas? Clarification of this point is associated with Debbie Purdy, a woman with multiple sclerosis, who in 2009 won a case in the High Court seeking assurances that her husband would not be prosecuted if he accompanied her to Switzerland. The Law Lords agreed that the law was unclear and subsequently the Director of Public Prosecutions published new guidelines in 2010 clarifying the factors that would be taken into account when making a decision about prosecution. These include consideration of the person's ability to make a clear informed decision about their suicide and the motivation of the person accompanying them (Pattinson 2011). However, it is important to note that the guidelines are neither embodied in nor change the law. If Peter and Clare decide to accompany Susan to Switzerland, they may still be questioned by the police on their return and therefore there is still a chance that they could face prosecution. While up to October 2015, 117 cases of assisted suicide have been referred to the Crown Prosecution Service by the police, not all of these involve individuals using Dignitas, and to date no individuals accompanying patients to Switzerland have been prosecuted (Director of Public Prosecutions 2016).

Despite the defeat of the Assisted Dying Bill, there is still a debate about the morality of assisted dying. Proponents of euthanasia (such as members of the UK organisation Dignity in Dying) campaign for changes to be made in the law to allow not only physician assisted suicide, but for health professionals to administer medication to terminally ill patients with the explicit intention of killing them; so called active voluntary euthanasia.

Returning to Susan and her family:

Peter and Clare tell Susan they don't want to accompany her to Switzerland and while they have sympathy with her view, they don't think they should have to take the risk of facing prosecution. Together they decide to approach Dr Ahmed, Susan's GP, to ask her if, when the time comes, she will help Susan to die and administer a dose of lethal medication if necessary.

Administering lethal medication with the intent to kill a person is, in the UK, considered to be murder, irrespective of the motive or whether it is at the person's request. Therefore, should Dr. Ahmed agree to Susan's request she will be liable to prosecution and face a mandatory life sentence if found guilty.

Euthanasia is one of the most emotive and controversial ethical subjects facing practitioners. While the law and professional body guidance is clear, there is some evidence to suggest that the general public are more supportive of changes to the law to allow active voluntary euthanasia (YouGov 2014). Dr. Ahmed does have some options available to her, in that she may prescribe and administer medication to control Susan's pain which may have the unintentional effect of hastening her death. The argument used to justify this draws on the Doctrine of Double Effect[2] whereby a doctor may legitimately use strong analgesics or sedatives even if this might risk hastening death, provided their intention is to relieve suffering and the prescription is in keeping with that intention (General Medical Council 2013). This is not only permissible in law, but along with withholding and withdrawing treatment (defined as passive euthanasia), is considered to be good practice by experts in palliative care.

However, some ethicists, most notably James Rachels (1997), raise moral objections to permitting one practice (e.g. the prescription of strong analgesics or sedatives to relieve pain but which is also very likely to hasten death) while forbidding the other (i.e. the administration of a dose of lethal medication in order to hasten death). Discussing this in terms of active and passive euthanasia, Rachels famously asks his readers to engage in a thought experiment regarding Smith and Jones who both stand to gain if their six-year-old cousin dies. Smith sneaks into the bathroom while his cousin is in the bath and drowns the child. Jones is going to do the same thing, but on entering the bathroom, he sees his cousin hit his head and fall face down in the water. The child drowns and Jones does not intervene.

For Rachels, the actions of Smith cannot be described as morally worse over the omissions of Jones because Smith deliberately drowned the child. Nor can Jones's failure to act be considered to be morally more preferable than the actions of Smith, because Jones did not deliberately drown the child but simply failed to rescue him when he could easily have done so. The key to this dilemma for Rachels is that the intention of both Smith and Jones was the same. Rachels extrapolates from this that to condemn active euthanasia while condoning passive euthanasia is illogical. Of course the most obvious objection to this example is that we cannot compare the intention of a healthcare professional intent on helping their patient to that of someone whose intention is based on monetary gain. But the point that Rachels makes focuses more on the concept of intent rather than the specifics of the example itself. Therefore, if the intention is the same, we may question whether it makes any difference how it is achieved. Intent is crucially important for the Doctrine of Double Effect, where the intention of the health professional administering potentially life shortening medication is to alleviate suffering. While it may be argued that this is entirely different to the scenario posed by Rachels, using the Doctrine of Double effect to justify distinctions between acts and omissions has been criticised as encouraging health professionals to engage in hypocrisy rather than being honest about their actions (Begley 1998).

Even if you are persuaded by Rachels's argument regarding acts and omissions, it does not necessarily follow that you are committed to accepting that active euthanasia is morally permissible. For others, the fear of allowing active voluntary euthanasia is the worry that we will slide down a slippery slope to permitting involuntary euthanasia. So while active voluntary euthanasia in itself may be ethically justified,

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[2] The doctrine of double effect means that while it is always wrong intentionally to perform a bad act for the sake of the good consequences that may arise, it may be permissible to perform a good act in the knowledge that unintended bad consequences will arise.

the concern is that it will lead to complacency and result in euthanasia without consent where the person lacks capacity for example, through brain injury or progressive conditions such as dementia. The existence of a slippery slope is disputed, but for some further insight we can look to the experience of Belgium, Luxembourg, and the Netherlands where active voluntary euthanasia is permissible in law. The Netherlands has had formal legislation permitting euthanasia since 2001, but the practice was common for several years before this, if carried out according to the professional guidelines of the Royal Dutch Medical Association. Cases of euthanasia are reported to regional review committees in the Netherlands and data is freely available. However, the data is open to interpretation with proponents of euthanasia citing the Netherlands as an example of good practice, while those who condemn the practice question the true voluntariness of the decisions. Whether this is evidence of complacency and sliding down the slippery slope is also open to debate. However, it is clear that the most recent published data in 2013 shows the number of reported cases as 4829. This is more than double the 1882 cases recorded in the first year following legalisation (British Medical Association 2016).

In Susan's case it is highly unlikely, although not impossible, that Dr. Ahmed will agree to Susan's request and deliberately give her lethal medication with the express intent of ending her life. To do so would be very risky for both Dr. Ahmed's professional registration and perhaps more importantly her liberty. This isn't to say of course that Dr. Ahmed necessarily disagrees with active voluntary euthanasia in principle. It simply indicates that she is not prepared to carry it out, even if it seems to be in Susan's best interests and she is convinced that Susan has the capacity to make the decision. While the subject remains highly controversial and permissible in other European countries, in light of recent unsuccessful attempts to change the law on physician assisted dying in England and Wales and Scotland, it is unlikely that any of the UK parliaments will even debate, let alone approve, the more radical step of legalising euthanasia in the near future.

Conclusion

The ethical issues that arise when caring for patients at the end of life pose a challenge for healthcare professionals. Over the last 10 years there have been a plethora of advisory documents produced by charitable and government organisations on the provision and delivery of palliative care showing a clear commitment to ensure good quality care irrespective of where patients spend the last days of their life. Despite complex funding arrangements for palliative care, the UK is considered to be a leader in the development of this speciality particularly through the hospice movement. While practitioners will undoubtedly want to deliver care commensurate with the very highest standards, for some individuals there appears to be a discrepancy between the care they want and perhaps feel they are entitled to receive, and the reality of what services can be provided. This is particularly noticeable in the assisted dying debate where the attitudes of the public seem to be at odds with both healthcare professionals and legislative bodies. In the absence of any likely changes in the near future to allow individuals to make lawful decisions about the place and time of their death, some will take matters into their own hands and continue to use the services of Dignitas. But ensuring the provision of a good death will in many cases fall to healthcare professionals across a broad spectrum of care services, not just specialists in palliative care. Therefore it is crucially important that lessons are learned from the failure of the LCP, and that adequate funding for education and training is made available to make certain that the principles and guidance in '*One Chance to Get it Right*' are a reality and not merely aspirational.

Key Learning Points

- Ensuring patients have a choice regarding their place of death and access to expert care is essential to facilitate a good death.
- New guidance '*One Chance to Get it Right*' published in 2014 focusing on individualised care and good communication in end of life care replaced the discredited Liverpool Care Pathway.
- Treatment that is costly and ineffective is of no benefit to a patient on an individual level nor does it demonstrate good use of resources.
- The withdrawal of nutrition and hydration administered by artificial means remains a controversial issue despite being classed as medical treatment that can in some circumstances be lawfully withdrawn.
- Attempts to bring about changes to the law to allow physician assisted dying in England, Wales, and Scotland have been unsuccessful, although this is allowed in other countries including Canada and Switzerland.
- The Suicide Act 1995 prohibits aiding and abetting suicide, but several individuals travel each year from the UK to use the services of Dignitas accompanied by relatives who risk prosecution.

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Ethical Issues in Mental Health Nursing

11

Grahame Smith

Abstract

This chapter explores mental health nursing practice within an ethics context. It teases out the ethical challenges that mental health nurses can face on a daily basis. A short case-study highlights potential solutions to those challenges.

For mental health nurses having the power to control and being expected to control people diagnosed with a mental disorder can be morally distressing, especially where situations do not always have clear outcomes. The case-study part of the chapter will consider how in these difficult circumstances mental health nurses can control and potentially restrict service user freedoms in a way that reduces moral distress and is beneficent and sensitive. A challenge for the contemporary mental health nurse is to know how to wield this power in a way that acknowledges their societal responsibilities while at the same time respecting the rights of the individuals they are required to control. It is important to recognise that restricting freedoms through the use of sanctioned coercion can be a good thing, however this is dependent on coercion being used by the mental health nurse in a way that is sensitive to the needs of the mental health service user.

Keywords

Mental health nursing • Coercion • Ethical reasoning • Values-based practice • Expert practice • Emotional intelligence

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P.A. Scott (ed.), *Key Concepts and Issues in Nursing Ethics*,
DOI 10.1007/978-3-319-49250-6_11

Introduction

This chapter will explore mental health nursing within an ethics context. It will tease out the ethics of mental health nursing practice, presenting common ethical challenges mental health nurses face on a daily basis, providing a case-study example which will highlight potential solutions to those challenges.

On a daily basis mental health nurses make clinical decisions. These decisions have an ethical dimension, however this ethical dimension is not always acknowledged (Smith 2012). It does not necessarily follow that this lack of acknowledgement means mental health nurses are not ethical practitioners; clearly their practice will be framed by ethical rules and frameworks (Nursing and Midwifery Council (NMC) 2015). It is more the case that ethical reasoning and clinical decision-making have become so entwined it is hard to distinguish the difference, if indeed there is a difference. The competent mental health nurse will be adept at top-down ethical reasoning, using rules and frameworks, however to be expert they will need also to be bottom-up ethical reasoners (Smith 2012; Cohen 2004). In addition, mental health nursing practice has a unique aspect compared to other nursing fields of practice. In this field of practice it is the case that,

> …. a fully conscious adult patient of normal intelligence may be treated without consent, not for the protection of others (though this is also possible) but in their own interests (Fulford 2009, p. 62)

Being able to control people who have been diagnosed with a mental health condition is nothing new. Indeed there is an historical context for such intervention which this chapter will explore. Restricting services users'[1] freedoms can be morally distressing, even where it is justified and especially where situations do not always have clear outcomes (De Veer et al. 2013). In the case-study part of the chapter we will consider how in these difficult circumstances mental health nurses can restrict service user freedoms beneficently and sensitively.

The Context of Mental Health Nursing

Over 30 years ago the main ward door on an acute mental health ward in the English health system was not routinely locked. Fast forward to the twenty first century and these doors are now routinely locked. The practice of locking the main ward door is not in itself unusual. What is unusual is that they are kept locked all the time, which in some ways can be seen as a return to the restrictive practices of the past (Ashmore 2008). Keeping the door unlocked was a key component in the process of creating a therapeutic environment (Ashmore 2008). Bowers et al. (2010) describe a journey of 'door locking where in the 1960s and 1970s it was unusual to permanently lock

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[1] While recognising the debate in the literature around nomenclature patient / client / service user, see for example chapter seven of this book, the term service user is the term used in this chapter as that in most common usage in mental health care contexts in both Ireland and the UK.

the main ward door. By 2010 42% of ward doors were permanently locked. In 2015 the Care Quality Commission (CQC) reported that ‘86% of wards (1,109) had locked doors’ (p. 34) Care Quality Commission (CQC) (2015).

Locking doors certainly creates a potential ethical tension between keeping mental health service users’ safe, protecting the vulnerable, and eroding freedoms and being paternalistic (Bowers et al. 2010). At this juncture it would be useful to consider within an historical context why society has this imperative. Morse (1977) makes the following observation;

> For hundreds of years, the Anglo-American legal system has been developing special rules for dealing with problems caused by the inherently perplexing phenomenon of mentally disordered behavior (Morse 1977, p. 529)

In madness: a brief history (2002) Roy Porter describes madness as being potentially as old as mankind. Porter (2002) supports this view by citing the ancient art of trepanning, where holes were drilled into a person’s skulls to allow ‘devils’ to escape. At this time madness was viewed as a punishment, where the gods would smite people with madness for committing a perceived wrong (Porter 2002). In early Christian times madness could be good or bad. It was good in the case of saintly visions. Inevitably it was only bad, satanic possession that needed to be dealt with and exorcised (Porter 2002). Around the Enlightenment (1620s–1780s) madness was starting to be viewed by some as a nervous system defect. This was the start of viewing madness as a medical condition. During this period locking up people who were viewed as mad would only happen if their family or the local community could not take care of them, and sometimes if they were viewed as being dangerous (Porter 2002). According to Porter (2002) in England only 5000 people out of a population of 10 million were held in asylums in 1800. At this time the medical discipline of psychiatry started to form, with the requirement that asylums were licensed and that they had a medical presence.

The standards of care in these facilities varied greatly irrespective of whether they were funded privately or by charitable donations. Physical punishment was not uncommon however some asylums offered rest and recuperation (Porter 2002). The legal system started to create special rules for people who were not necessarily committing crime, but whose behaviour was pejoratively viewed as not being the norm (Morse 1977). Demonstrating ‘abnormal’ behaviour in itself was not an issue; it only became an issue to control when the person was also viewed as not being socially responsible (Morse 1977). Creating special rules to manage what we would now view as mental distress was the start of society perceiving mental health conditions as a risk (Morse 1977). Society wanting to control behaviour that is perceived as a risk is nothing new. Throughout history political philosophers have explored this issue however they have always paid scant attention to risky behaviour arising from a person’s mental distress (Wolff 2006).

Over time, as societal norms and rules developed, people on a day by day basis were expected to abide and sign-up to these rules - even if this was a tacit process. The aim of these rules was to prevent people engaging in destructive behaviours including self-destructive behaviours (Wolff 2006). By abiding by these rules a person was given certain freedoms. If they broke these rules, such as committing a crime, these freedoms could be taken away as a form of punishment (Wolff 2006). This position does not consider rule-breaking behaviour where a person may break the rules due to a mental disorder. Where it is briefly considered, the general view is that people with a mental disorder who break the rules should not be punished they should be protected, even if this process restricts freedoms and in effect looks like a form of punishment (Wolff 2006).

In the early days of the asylums nursing as a profession did not exist, neither did psychiatry as a medical discipline. It is only since the 1930s that mental health nursing started to become recognised as a future field of nursing practice (Nolan 1993). Mental health nursing within a UK context has always been closely aligned with the medical discipline of psychiatry; as this discipline started to form in the 1800s mental health nursing practice also stated to take shape (Porter 2002; Nolan 1993). It is important to recognise mental health nurses have not always been called mental health nurses, throughout the ages they have had different titles such as keeper and attendant (Nolan 1993).

The role of the keeper started to emerge during the 1800s with the emergence of the asylums. The job of the keeper was to look after the institution, control the 'inmates', and where required be a servant to the doctor who was in charge of the asylum (Nolan 1993). As the asylums became more numerous and at the same time started to focus on the treatment of mental distress, the keeper role started to transform into the role of attendant (Nolan 1993). At this time there was the belief that mental health conditions should and could be treated and possibly 'cured' (Porter 2002). The role of the attendant was to assist in the delivery of these cures, which included anything from good basic care, exercise, and good nutrition, to activities such as fettering (tying people down), and blood-letting (Porter 2002; Nolan 1993). Similar to be the keeper role attendants tended to be un-trained, however this changed in 1889 where attendants were required to attend a national training course. From 1923 female attendants started to be called nurses, and male attendants began to gain this title from 1926 (Nolan 1993).

With the change of title from attendant to nurse there was a greater emphasis on the delivery of good basic care. More technical elements of care were in their infancy (Nolan 1993). Over time the notion of healing and curing within mental health care, started to incorporate psychiatric medication and talking therapies as important elements. Observation and control of people incarcerated in asylums were also important, however they became less explicit and more implicit as treatments such as fettering started to disappear (Nolan 1993; Roberts 2005). Treating mental distress in this way was continuing to be influenced by the medicalisation of madness; involving describing different forms of mental distress and developing different forms of treatments (Porter 2002). With the promise of treatment came the promise that irrationality could be controlled. At the forefront of controlling irrationality was the mental health nurse (Roberts 2005). Fast forward to the present day the challenge, for the contemporary mental health nurse, is to know how to wield this power to control in a way that acknowledges their societal responsibilities, while at the same time respecting the rights of the individuals they are required to control.

The Moral Domain of Practice

Having the power to control and being expected to control people with mental health conditions has been shaped by the historical development of mental health nursing practice; it has also been shaped by the media and by public perceptions (Smith 2012). Over recent years the media have covered high profile incidents of people with mental health conditions in a way that portrays people with mental health conditions as being more risky than so called ‘normal people’ (Wood et al. 2014; Johnson 2013). In addition, mental health services are usually portrayed as failing. This tends to be based on the view that they did not control the individual and in turn prevent the incident from happening (Wood et al. 2014; Johnson 2013). Driven by this societal expectation that people with mental health conditions should be controlled, mental health legislation has also been applied in a more controlling manner such as the increase in compulsory admissions to mental health services (Robert 2005; Johnson 2013).

Of course contemporary mental health nursing has moved away from the brutalities of the past in the way that people with mental health conditions were confined, conformed, and treated (Nolan 1993; Roberts 2005). The emphasis of contemporary mental health nursing practice is to be evidence-based and to be ethical, which includes abiding by the nursing profession’s ethical rules (Smith 2012; NMC 2015). That does not mean that interventions which confine and conform do not take place or that some treatments are not controversial, such as electroconvulsive treatment (ECT). However, if these practices are used in an unethical way mental health nurses are held to account (NMC 2015). It is important to recognise that these practices have an explicit and an implicit dimension. Explicit interventions include the use of mental health law, physical restraint, environmental control such as seclusion and locking wards, and the use of medication (Roberts 2005). Implicit interventions are more subtle; they are day to day interventions which the nurse may not recognise as having a controlling element. These include such interventions as observing and monitoring the service user, making clinical judgements and recording them, assessing including the assessment of risk, psycho-social interventions, and reviewing a service user’s care (Roberts 2005). The impact of both explicit and implicit interventions is that the service user knows they are being monitored. They know that if they do not conform and exhibit ‘normal behaviours’ their freedoms could be restricted. They also know they have to demonstrate conformity; in other words they have to control themselves (Roberts 2005).

Explicit interventions can be viewed as directly coercive, overtly restricting a service user’s freedoms, whereas implicit interventions allow an element of choice. However, the service user is being pressured to behave in ways that the mental health nurse and society expects them to behave (Smith, 2012; Roberts 2005).

Having this sanctioned power to coerce and apply pressure emanates from a service user being labelled as having a mental health condition. Irrespective of the heated debates surrounding the use of these labels the outcome is the same. The mental health nurse has the power to control the individual with a diagnosed mental health condition (Roberts 2005). A check and balance to the use of this power is that the mental health nurse will follow the rules, including legislation, polices, and professional codes (Smith 2012). The challenge with a rules-based approach is that it is more suited to making clinical decisions when a situation is not complex; when there is plenty of time to make the decision and the outcome is relatively certain (Smith 2012). The reality of everyday clinical practice is that this is not usually the case. Certainty of outcome, for example, can be a luxury rather than a given. Irrespective of this uncertainty the mental health nurse will still have to make decisions which have to be justified; this may include providing evidence of the right motives and/or the right outcomes (NMC 2015).

Ethical decision making within a mental health nursing context is not just a rational process it is also an emotional process, one that requires a high degree of self-awareness (Roberts 2004). This is coupled with the need to maintain a therapeutic relationship, which is the medium for treatment (Smith 2012). In the process of navigating an ethical way through this complexity the mental health nurse will rely on their professional knowledge and their ability to reason (Smith 2012). Reasoning and professional knowledge are not separate activities. They complement each other. They do not happen in a vacuum. Ethical reasoning which builds on good professional knowledge (bottom-up reasoning) will have external points of reference (top-down reasoning) (Cohen 2004). External points of reference include professional frameworks and codes, legal frameworks and policies, clinical guidelines, and ethical theories (Smith 2012). These rules are there to guide the mental health nurse. However, these frameworks do not always provide specific answers, even if the nurse would like this to be the case; there is always a level of interpretation required (Smith 2012). In addition, these frameworks can provide conflicting advice and on this basis the nurse not only has to interpret they also have to know which rules to apply, when to apply them, and how they should be applied (Smith 2012).

Being ethical is a balancing act regardless of the expertise of the mental health nurse. There is a constant need to respect autonomy while recognising that mental health care can be inherently paternalistic and controlling (Smith 2012). Making sense of autonomy within mental health care is a challenge, especially in light of the fact that most ethical theories are developed with the rational person in mind. However, principlism[2] does take a position on the person who has a mental health condition. Beauchamp and Childress (2013) highlight that being paternalistic is justified as the person's condition prevents rational deliberation, free choice, and action and therefore the person is non-autonomous. Paternalism is justified on the grounds of beneficence or nonmaleficence. This position appears quite straightforward. The weakness of this approach, however, is that judgement of whether a person is

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[2] Principlism describes an approach to ethical decision-making using ethical principles; such as the four-principle approach of Beauchamps and Childress (2013) cited above.

non-autonomous is based on the mental health nurse using what appears to be facts such as ‘mental illness’ and ‘lack of capacity’. These concepts are ‘values turned into facts’ or value-laden judgements (Fulford 2009). The effect being that restricting a service user’s freedom is dependent on the viewpoint of a moral agent and the one who holds the power; the mental health nurse (Fulford 2009).

Establishing whether a mental health service user is non-autonomous is an ethically complicated matter. Some authors such as Roberts (2004) offer a pragmatic solution to the ethical challenges inherent within mental health care by combining a principle-based approach with other ethical approaches. Taking this pragmatic approach gives the nurse the scope to look first at the uniqueness of their practice, as a bottom-up reasoner, and then decide which ethical theories enable them to reach an agreed solution, as a bottom-up to top-down reasoner (Cohen 2004; Roberts 2004). An example of such an approach may be where a mental health service user demonstrates risky behaviour and the mental health nurse wants to keep them safe; a good outcome which links to a number of ethical theories. The mental health nurse has the sanctioned power to restrict their freedoms; however as a bottom-up to top-down reasoner they will recognise the importance of achieving a good outcome for all parties. The outcome will need to keep the service user safe while at the same time maintaining the therapeutic relationship; essentially being person-centred. To achieve this the nurse will use practice-orientated skills, such as the use of the therapeutic self, to explore and deliver a solution which in effect should follow the least restrictive path available.

Ethical Challenges

It is important to recognise that coercion can be a good thing. The Department of Mental Health and Learning Disability (2006) Report, what is now known as City 128 Report, was an extensive piece of research focusing on understanding and identifying the mental health nursing interventions that produce both a controlled and therapeutic environment. The report infers that coercive strategies when used to benefit the service user can be a good thing (Department of Mental Health and Learning Disability 2006). This is, however, dependent upon these strategies being used in a way that is sensitive to the needs of the mental health service user.

The City 128 Report does not specifically look at implicit interventions, neither does it consider mental health nursing in the community. However it does highlight that ‘sensitive’ coercion which reduces the emotional intensity of mental distress is a good thing, thereby placing this notion within an ethical context. A good starting place to consider what sensitive coercion may look like or how it should be applied would be to explore the notion of coercion in more depth. There are a number of political philosophers who have written about the issue of coercion. Likewise there are a number of articles within the field of mental health nursing that touch upon the issue of coercion. The obvious difference between these perspectives is that political philosophers focus on coercion within a ‘rational person in society’ context, whereas mental health nurses are trying to understand coercion within an ‘irrational person in society' context. This does not mean lessons cannot be learnt from both perspectives; however there is a need to reconcile and interpret one perspective with the other. The work of the political philosopher Ripstein (2004) provides a solid base in which to start this process.

Coercion can be seen as a way of getting individuals to do or not do something. It also diminishes the individual's freedoms and on this basis it is a violation of an individual's rights' (Anderson 2011). This also includes the threat of being coerced. Carr (1988) highlights that the threat of coercion ultimately restricts an individual's freedom; in effect their freedoms are dependent on meeting certain conditions. Generally coercion, including the threat of coercion, is justified and authorised where it prevents societal harms (Ripstein, 2004). According to Ripstein (2004) *'both the use of official force and the claim of states to tell people what to do are justified because, in their absence, arbitrary individual force prevails, even if people act in good faith'* (p. 3).

The authorisation of coercion is transferrable to mental health nursing practice. If it is used in accordance with mental health law, it can be seen as justified. If it is not sanctioned, it is not justified (Ripstein 2004). However, while coercing someone who is 'rational' usually relates to preventing societal harms, it can also be a form of punishment. Someone who is deemed to have a mental health condition can be coerced not only to prevent societal harms, but also to prevent them from harming themselves, on the basis of the best interests argument (Morse 1977; Roberts 2005). Acting on behalf of someone, in their best interests, can make understanding the coercive nature of mental health nursing practice more difficult: 'I'm not really using coercion I am acting in their best interests' (Roberts 2005). This is usually justified by, 'the person is irrational and no longer free and therefore I have to act and restrict what a rational person would call freedoms, and if they were rational they would agree with my actions' (Smith 2012; O'Brien and Golding 2003).

The work of O'Brien and Golding (2003) tries to move this debate forward by first defining coercion within a mental health nursing context; '*any use of authority by the mental health nurse to override the choices of the service user*' (p. 68).

O'Brien and Golding (2003) then assert that coercion in all its forms is only justified where;

- The service user lacks capacity
- The harms prevented or benefits provided outweigh the harms caused by the coercive act
- The least coercive intervention that will promote good or prevent harm is used

O'Brien and Golding (2003) are contending that 'best interests' should not be a catch-all phrase which justifies the uses of coercion (p. 172). O'Brien and Golding (2003) make a valuable contribution to the debate; however, measuring capacity, weighing outcomes, and deciding on the least coercive strategy are values and ones that are dependent on the rational viewpoint of the nurse (Fulford 2009). As an example a service user wants to leave the ward but they are openly expressing ideas of harm to self and others and they lack capacity. To keep the service user on the ward would increase the chances of preventing harm and it would also increase the chances of treating the underlying mental disorder and therefore potentially reducing the risk of harm, an act that would benefit the service user (Roberts 2004). If persuading the service user does not stop them leaving the ward, you move on to locking the door and so on, it sounds pretty straightforward (O'Brien and Golding 2003). And yet there is an emotional dimension to such intervention. Stopping the service user leaving can be distressing for both the service user and the nurse. It can also impact negatively upon the therapeutic relationship which is the medium for treatment (Smith 2012). On this basis the nurse has to be rational and reasoned. They also have to be emotionally intelligent, with the ability to facilitate an open dialogue with the service user that shows an understanding of the power differences inherent within the relationship (Roberts 2005).

The work of O'Brien and Golding (2003), you could argue, provides a minimum standard of how coercion should be justified, a way of preventing the abuse of the nurse's power. In addition it has to be recognised that when delivering care in complex situations, what works in one situation may not work in another. Coercion is no different. A set of actions in one situation could be described as being beneficial, whereas in another but similar situation the same set of actions could be described as being harmful. The mental health nurse when using coercion has to be sensitive to the individual nature of a situation to ensure that the coercion is indeed beneficial. Being sensitive is based on responding in the right way. To do this the nurse will have to have the right character traits such as kindness, patience, tolerance, and compassion to name a few (Armstrong 2006; NMC 2015). In addition to these character traits the nurse will need to possess practical wisdom; the ability to make the right choice at the right time (Armstrong 2006; Smith 2012). By using coercion in a reasoned and emotionally sensitive way the outcomes of its use should benefit all parties.

A Case-Study

This section will highlight, through the use of a case-study, how the mental health nurse can emotionally and rationally reason through a number of ethical challenges.

Sam is 25 years old and lives at home with his mother. He has recently completed a further education course in business management and he is looking for a full-time job. He still works part-time at the local supermarket; however, his goal is to manage his own supermarket. Since completing his business management course a number of people including his mother have mentioned that he has become a 'bit excitable'. Sam does not know what this means, he just feels incredibly happy. He is aware that the 'voices' are talking to him more often and he has a secret; he has stopped taking his medication. He made the decision to stop taking his medication because he felt he would concentrate better and he was fed-up with putting on weight. He also decided not to tell anyone especially his mother as she would be upset with him.

A couple of weeks ago Sam did not arrive at work. His manager phoned Sam's mother wondering where Sam was. This phone-call was out of concern as he had noted that Sam was looking increasingly distracted and he was also not attending to his hygiene, which was out of character for Sam. His mother, in a panic, immediately phoned the police, just as Sam walked through the door. Sam became angry, accusing his mother of plotting behind his back and trying to stop him reaching his potential as a chosen one. Sam's mother was frightened and as she was still on the phone to the police asked for their help. Within minutes the police arrived and Sam, out of frustration and fear, struggled with the Police. Sam was assessed in the police cells first by a police surgeon and then by a member of the mental health liaison team. It was agreed that Sam should be admitted to hospital. Sam was reluctant, however he felt quite fearful being in a police cell so he agreed to be admitted for a period of 'assessment'. Sam arrived on the ward and he was offered medication which he refused and then went to bed. The next morning Sam was seen by a doctor and a nurse. He told them he wanted to go home. He was told that they would consider his request, however he needed to tell them about the events leading up to his admission. Sam told them about being special and that he hears voices. He is not sure whether they are angels or just entities called the 'helpers'. Sam also mentioned that since he had stopped taking his medication he has started to realise that agents called the 'shadows' were stopping him from achieving his goals. He was asked about his goals. Sam said his main goal was not clear until he was in the police cell and then he realised his goal was to 'purge the shadows'.

After being assessed Sam asked again about going home. He was told that he would need to stay on the ward for the time-being and he really needed to start taking his medication again. Sam became angry and stormed out of the office towards the ward door. He tried to push through the door. It was locked, and this frustrated Sam and he started to kick the door. People were suddenly telling him to calm down, and offering him medication. He lashed out. Suddenly he was on the floor; he knew he had been injected with medication. After being moved to a single room he started to cry. He briefly heard a nurse mention he was on a section of the mental health act. He did not care. He wanted to be left alone.

John is a third year mental health student and it is his first day on the ward today. Sam is mentioned in the morning handover and a brief overview is given. Sam is a 25-year-old male with a diagnosis of schizophrenia. He is on a section 3 of the mental health act (compulsory admission to mental health services for treatment); he hears voices and has delusions about being a 'messiah-like figure'. He stopped taking his medication around 4 months ago. This is his second psychotic episode. The first episode happened around 5 years ago and he did not need hospitalisation.

After the handover John says hello to Sam and goes to shake his hand, suggesting they have a chat. Sam tells John he is like the others and he does not want to talk. At the lunch time medication round Sam initially refuses his medication but takes it when he is reminded that he is on a section of the mental health act. Once he has taken his medication he opens his mouth to show he has taken it without prompting, and then leaves the trolley area muttering 'you are not sticking another needle in me'. On his next shift John decides that he will have a good chat with Sam. John approaches Sam *and starts a conversation; Sam immediately mentions that he will talk if he has to, 'because you're the boss, otherwise leave me alone, and phone my Mum - I want some clean clothes, but I do not want to talk with her as she put me in here'.*

John recognises that Sam has been through a tough time. He also recognises that Sam is controlling his own behaviour, possibly out of the fear of being coerced again (Roberts 2005). *John talks to his mentor about Sam to explore the best way forward. His mentor explains to John that Sam has been coerced however it will have always been for his benefit. In Sam's notes it mentions that he has been debriefed after the 'restraint' incident* (National Institute for Clinical Excellence (NICE) 2015). *John wonders if this is the case why Sam still appears to be upset and possibly resentful. John's mentor starts to explore with John the idea that even if a reasoned approach is used, this does not mean it will instantly remove conflict. John starts to embrace this idea of ambiguity; that not all things fit nicely into systems and models* (Cohen 2004; Smith 2012). *He is aware that the nursing team recognise that coercion is an ethical issue; the facts were explored before it was applied, it was adherent to professional, ethical, and legal rules and theories, and the team explored all alternative options including reflecting on the outcome* (Smith 2012). *John asked his mentor if he thought the use of coercion was right. His mentor said, 'yes, in certain circumstances, however even though it could be right, at an emotional level it may feel wrong'. His mentor went on to explain that coercion was more than just restraining and using medication, it could be about observing and monitoring, which has the effect of the service user controlling their behaviour to fit in* (Roberts 2005).

Taking this advice into account John started to think about the emotional impact of coercion and how he could work with Sam's perspective. John decided he would use a values-based approach when working with Sam to first understand Sam's perspective and then to resolve any ethical conflict through working with Sam's story and values in a person-centred way (Fulford 2009). *John meets with Sam again and takes the opportunity to encourage Sam to talk about his experiences. Through this process of listening to Sam's story John starts to gain an emotional insight into Sam's experiences and how it feels to be coerced* (Roberts 2005). *John also recognises that Sam's distress is not all about the act of coercion, it is also about feeling powerless. John realises there are lessons to be learnt, ones that give him the opportunity to understand what therapeutic approaches to use when working with Sam* (Roberts 2005; Smith 2012).

Reflecting on their conversation John recognises the importance of working with both facts and values; 'the two feet principle' (Fulford 2009). *Using this approach can help to resolve ethical conflict especially when using coercion, it is also recovery-focused* (Cleary et al. 2013). *In the long-term by engaging with Sam in this way John acknowledges that he will;*

- *Promote Sam's wellbeing*
- *Maximise opportunity for Sam*
- *Empower Sam to start to take control*
- *Facilitate and support Sam to find meaning and purpose*

Conclusion

The clinical decisions that mental health nurses make have an ethical dimension which is sometimes not acknowledged. This does not mean that mental health nurses are not ethical practitioners. It is more the case that ethical reasoning and clinical decision-making have become so entwined it is hard to distinguish the differences between the two. To be expert the mental health nurse has to be adept at both top-down and bottom-up ethical reasoning. Being able to do this means the nurse takes a more holistic approach which is person-centred and pays careful attention to the service user's needs, while at the same time acknowledging the regulatory and ethical frameworks that must influence and regulate mental health nursing practice.

Historically there has also been a propensity for society to expect the mental health nurse to have a controlling element to their practice. Controlling can be explicit, but, it can also be implicit. To make ethical sense of this controlling element a number of authors offer a pragmatic ethical approach which could potentially give the mental health nurse the opportunity to look first at the uniqueness of their practice, as a bottom-up reasoner, and the latitude to decide which ethical theories enable them to reach a reasonable and workable solution.

There is also an emotional dimension to mental health nursing, especially where the therapeutic relationship is the medium of treatment. Being emotionally sensitive is based on responding in the right way, using the right character traits, and possessing practical wisdom. Even when using coercion the mental health nurse should be emotionally sensitive and by doing so the outcomes should benefit all parties.

Key Learning Points

1. The ethical dimension of clinical decision-making within mental health nursing practice can sometimes be hidden.
2. Expert mental health nurses engage in ethical reasoning which is simultaneously top-down and bottom-up reasoning.
3. Mental health nurses have the explicit and implicit power to control mental health service users, however to achieve good outcomes for all parties the mental health nurse has to use this power sensitively.

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Resource Allocation and Rationing in Nursing Care

12

P. Anne Scott

Abstract

Public discussion of resourcing in health care tend to compound ideas of resource allocation and rationing. Public debate also tends to focus on situations of scarcity such as lack of kidneys or hearts for transplantation, or heated arguments regarding whether the latest very expensive new drug should be made available, regardless of cost, to treat certain condition such as Cystic Fibrosis or a particular type of cancer. The idea that nursing or medical time is an important health care resource that needs to be allocated with care rarely gets an effective airing in public debate.

I argue in this chapter that it is important in the healthcare context to differentiate resource allocation from rationing, on the basis that if we assume we are rationing health care as our starting point we may miss opportunities to examine more and less effective ways of allocating the health care resource. This is particularly important in nursing care where failure to examine carefully how the nursing resource is allocated, and supported, is leading to covert rationing of nursing time and sub-optimal patient care in hospitals across Europe.

Keywords

Resource allocation • Rationing • Care left undone • Covert rationing Nursing care

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P.A. Scott (ed.), *Key Concepts and Issues in Nursing Ethics*,
DOI 10.1007/978-3-319-49250-6_12

Introduction

Resource allocation in health and nursing care raises a number of important political, social and ethical issues. As populations increase, population demographics change and/or demand for health and nursing care outstrips supply, this moves us either to make a decision to increase investment in health care, redistribute resources from lower priority services to those of higher priority, or limit access to the services that exist – the latter is called rationing of health care.

Decisions regarding resource allocation and rationing in health care, though potentially highly emotive, are important political and social decisions and thus should receive careful attention, analysis and consideration. This chapter aims to explore issues of resource allocation and rationing, within the context of nursing practice and the provision of nursing care.

Health care resource-related discussions, which reach the public domain, often focus on headline grabbing issues such as whether a particular life-saving treatment should be provided by the relevant national health system (NHS in the UK or the HSE in Ireland) regardless of cost, organ transplants and shortage of organs, or whether particular groups in society, such as smokers, the obese and the elderly, should receive the same access to health care as those who exercise, look after their health or are young, tax-paying adults with caring responsibilities.

To date, the topic of resource allocation in nursing has not generated extensive, public discussion. However recent inquiries such as the Francis Inquiry in England (Francis 2010, 2013), the Vale of Leven Inquiry in Scotland (Vale of Leven 2014), and the Tallaght Hospital, Halapanaver and Portlaoise Hospital inquiries in Ireland (HIQA 2012, 2013, 2015) all have important things to say about the nursing resource and its impact on patient care.

Similarly, since the early years of this century, the work of Linda Aiken and her team, across a variety of health systems and countries (in the USA, UK and Europe) is suggesting a clear pattern in terms of the correlation between nurse staffing, nurse education levels and the outcomes for patients in acute surgical wards (Aiken et al. 2002, 2003, 2014; Rafftery et al. 2007).

All of the above would seem to suggest that it is timely to explore issues of resource allocation and rationing and its relevance for nursing and the provision of nursing care. This is particularly the case as we know that in a number of countries, including Ireland, the impact of the recent recession and the imposition of austerity measures across the public sector has had a direct impact on front line staffing in the health service. For example the Irish health system has experienced the loss of 5,000 nursing and midwifery posts from the sector between the years 2009 and 2014. Currently there are three thousand fewer front line nursing and midwifery staff in the Irish health system than was the case in 2007 (WIN 2016). This reduction in staffing has happened at a time when the general population continues to increase, with significant pressures emerging across both acute hospital and community services.

> A couple of years ago you would come on duty, sit down and consider how you would best allocate staff across the Emergency Department (ED) in order to get through the work, care for our patients and make the best use of the staff and skill set you had. Now its "what do we need to do to survive the shift" (Nurse Manager, busy Dublin ED, Summer 2016).

Resource Allocation and Rationing: Some Definitions

Resource allocation refers to the allocation of resources to a service, department or project.

It is important, at the outset, to differentiate between resource allocation and rationing. These are related but nonetheless distinct notions. In allocating resources we are making decisions regarding how to distribute the available resources. There is an implicit assumption that, broadly speaking, there is enough of the resources in question to go around. In situations of rationing, by definition, we are starting from a position that there is not enough of the particular resource to satisfy the needs of all those requiring it.

Focusing on the medical context, Caplan (1992, p. 322) defines rationing as follows:

> In the health care setting, rationing can be defined as a conscious, reasoned decision by a health care provider faced with irremediable scarcity to deny access to life-extending medical interventions or to interventions that can help restore or ameliorate serious dysfunction for some patients or for a group of patients. Rationing presumes that the health care interventions are both desired and known to be effective.

This is a much narrower definition of rationing than one may meet in the economics and ethics literature, where the notion of rationing may be used to cover any allocation decision. However Caplan argues for a narrower, more focused definition and continues:

> ... in health care, rationing refers to a very well-defined subset of allocation policies – those which require a conscious decision or the adoption of an explicit policy wherein certain persons of known medical need are excluded from treatment that might save, prolong, or significantly enhance the quality of their lives.
>
> The stakes are high where rationing in health care is concerned. Thus the overriding moral imperative with respect to rationing in the health care system is not to determine what criteria or rules are fair. It is to make sure that, in the face of apparent scarcity, there is no distributional policy which is a viable alternative to rationing. (p. 322)

The point being made here is that although rationing may occur at the level of both general and specific allocation decisions, not all allocation decisions are rationing decisions. That is, not all allocation decisions contain the conscious choice to give some patients significantly less than optimal care and/or let some patients die, while other patients will receive optimal care/the care that they need to continue living.

However Teutsch and Rechel (2012, p. 2) suggest that

> At some level, all resources are scarce and that is certainly true for health care. In the face of scarcity, resources are either explicitly or implicitly rationed. Rationing of health care limits access to beneficial health care services. The central question, then is not whether health care is rationed, but how, by whom and to what degree. The ethical dilemma is how to balance the precepts of autonomy, beneficence and distributive justice.

Maria Schubert, a Swiss scholar who has published some of the first work in Europe exploring rationing in nursing, defines rationing of nursing care as:

> … the withholding or failure to carry out necessary nursing tasks due to inadequate time, staffing level and skill mix (Schubert et al. 2008, p. 228)

In a development of Schubert's position a recent successful COST Action[1] grant application defined rationing in nursing care as follows:

> Rationing of nursing care occurs when resources are not sufficient to provide necessary care to all patients. The reason for this phenomenon include staff reductions, increased demands for care due to the technological advancements, more treatment options, more informed service users, all requiring more time and attention from care professionals. Rationing of nursing care may also occur due to particular approaches of nurses' clinical judgement and knowledge in allocating the resources and the wider value basis of society on care. As a result, fundamental patient needs may not be fulfilled and human rights linked to discrimination may be affected. RANCARE (2016, Technical Annex, Overview Summary p. 3)

Consideration of the different positions, presented in the above definitions, seems important for a number of reasons. For example it does seem that Caplan is correct to draw a distinction between resource allocation and rationing. In resource allocation we allocate the resources we have, one's salary for example, to do particular things – pay our mortgage, buy food, clothes, entertainment, and so forth. In an ideal world we may wish we had slightly more resource to allocate. However generally there is enough to go around and no one loses out significantly in the allocation. Allocating family budget for a holiday might be an example here. If Family A had €10,000 to spend they might chooses to go on a 10-day cruise on the Mediterranean. However because they actually only have €5,000 to allocate towards a holiday, they choose a very pleasant two week holiday on Lake Garda. While a cruise on the Mediterranean is still a dream to be worked towards, the family are happy.

In the nursing context let us imagine that there are 12 staff on Medical Ward B – this is, in general, an adequate number of nurses to provide the required patient care, assuming staff work at a reasonable pace and there are no more than the normal admissions, discharges and activity demands. Staff are allocated according to the model of care being used and the normal patient care is given during the nursing shift. However, if one morning the nurse in charge comes on duty and the normal 12 members of staff is reduced to 8, as a result of illness or other reasons, then she may well have to consider how to ration care to some patients in order to ensure that others get the care they require. This should involve explicit discussion, agreement and direction at the nursing hand-over and reporting period at the commencement of and throughout the particular shift – in order to try to ensure some degree of transparency, fairness and peer review of the rationing decisions. The nurse in-charge will also alert the central nursing office in order to try to get additional help

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[1] COST Action grants are research and innovation networking grants funded by the European Commission to enable transnational co-operation. For further information please visit the COST website: http://www.cost.eu/about_cost.

for this particular shift, so that the depleted nursing resource can be augmented, by agency nurses or nurses “on loan” from a quieter part of the hospital - to try to maintain the normal, good standard of care provided to the patients on Ward B.

In the context of reduced staffing, or perceived inadequate staffing, it is relevant to explore some implications of not making the staffing resource issues explicit. Let us return briefly to Alice whom we met in Chap. 8 (please see p. 102 above). Alice seems to have very little nursing resource allocated to her. This gives rise to a number of questions such as “Why has Alice received little nursing care/nursing resource?”; “Who has made the decision that Alice will not have nursing care and on what basis?”; “Who is aware of the decision to ration the nursing care that Alice is to receive?” “Has this been discussed with Alice, her parents, her medical team?” Nursing care is a social resource. Alice is in hospital because her doctor has decided that she needs medical and nursing care. Given the description in her case study it could be argued that Alice is not getting what she needs from nursing staff – what is due to her as a patient.

In Alice’s case it seems pertinent to ask who determined that there is not enough nursing time/care to go around? Who is responsible for the decision to ration nursing care, if it is perceived that there is not enough nursing care to go around? Who is accountable for the decision to ration nursing care? What is the basis for the decision? Who knows about the decision? Are the nurses on Alice’s ward aware, as a collective staff group, that Alice is receiving little or no nursing care – or has Alice somehow become “invisible” to nursing staff; is she being actively discriminated against for whatever reason? Is the decision to ration nursing care explicit or implicit – and does this matter? How is the rationing of care monitored? Who maintains oversight of care rationing and is accountable for the impact on patient care? Are there any other factors that can help with more effective allocation of the nursing resource available and thus potentially reduce or remove the need to ration nursing care in certain contexts and circumstances? It would seem that implicit rationing decisions are particularly problematic as, by definition, these decisions are unlikely to be transparent, or open to review. Implicit rationing decisions therefore also do not provide the stimulus or opportunity to consider alternative ways of allocating the available nursing resource, which may remove the need to ration nursing care in the first place.

What Do We Know?

Nurse and midwifery staffing in the Irish acute hospital sector, like many similar national systems, is largely historical. Little, if any, attempt has been made to adjust this historical nursing staff compliment in recognition of increasing population, changing demographic, increased acuity and dependency of patients or the increased patient turnover that has resulted from decreased length of hospital stay (Scott et al. 2013). It seems reasonable to expect that these changing pattern of demand would have some impact on the numbers of nursing staff required to organise and provide care.

The first national survey of nurses working in medical and surgical wards across the Irish acute hospital sector was carried out in 2009/2010 (Scott et al. 2013). Findings from this national survey provide insight into both the level and type of nursing work reported as "left undone" due to time constraints. The study also provides data on the levels of non-nursing work reported to be engaged in frequently by nurses across the acute hospital sector. Ball et al. (2013) in the UK and Ausserhofer et al. (2014) in a Europe-wide study provide similar information on the types of nursing care activities that nurses report as regularly left undone due to time pressures/shortages of nursing staff. What the findings of each of these three studies suggest is that nurses are either implicitly or explicitly rationing care to patients because, from the nurses' perspective, there is not enough time to provide the amount of nursing care required. These findings suggest that we need to engage in discussion about resource allocation and rationing in nursing.

However there is also growing evidence to suggest that there is a need to recognise the impact of factors such as the working environment, nurse characteristics and leadership on the quality of nursing care provided to patients. Aiken et al. (2011) suggests that some of the more detrimental effects of nurse staffing shortages can be ameliorated, to some extent, by a positive work environment, inclusive of supportive nursing leadership. Aiken et al. (2014) suggest that staffing wards with nurses who have degree-level education, or above, can have an impact on 30-day mortality rates of surgical patients. Papastavrou et al. (2012) argue that both team working and nursing leadership impacts on the covert/implicit rationing of nursing care; increasing the effectiveness of team working reduces implicit rationing of nursing care, as does increasing nursing leadership.

These studies appear to provide support for Caplan's demand that instead of focusing on devising fair rules for rationing as our starting point, we should begin by identifying when we are making implicit or explicit decisions to ration and make sure that there is no alternative – no better way of distributing our limited resources – that would avoid or minimise rationing. The potential impact of enhanced team working, nurse education levels and nursing leadership on the effective use of the nursing resource, seem important issues to explore in enhancing patient care and avoiding what may be unrecognised, unmonitored, implicit rationing of nursing care. This is also an important reason to argue for explicit rather than implicit rationing of nursing care.

Decisions regarding the allocation of resources for and within health care are broadly seen to be taken at three different, often interacting, levels. I argue below that nurses should recognize the possibility of contributing to discussions at each of these three levels because they have a civic, moral, and professional responsibility to make this contribution.

Resource Allocation and Rationing

The three broad levels of resource allocation are: macro level allocation, meso level allocation and micro level allocation. These different levels will be described briefly below.

The most general level of decision-making in resource allocation is at the macro level. This is the level at which the government, through the Ministry of Finance, decides the size of the health budget compared, for example, with the budget for education, social welfare, or defence. From this macro decision-making level the extent of the resources budgeted for health care, relative to other social needs such as education, becomes clear. There may be disagreement, among various government departments and/or vested interests, regarding the proportion of funds allocated to health as against education, for example. However, regardless of such concerns and disagreement, the purse available to health care will, inevitably, be finite, as indicated by the quotation from Teutsch and Rechel (2012) above (p. 161). The influence that the individual practitioner, in a democratic country, can have at this level is as a voting citizen. Pressure groups from within the health care professions may also have an influence at this level. If sufficiently well-organized there is potential to be much more effective as a collective as opposed to as an individual voter. It is at this level also that the public discussion of health care costs, the resources available, and potential criteria for explicit rationing of some elements of health care, when deemed necessary, can help inform government policy and decision makers.

The next level of decreasing generality is termed the meso-economic level (Coulter and Ham 2000), however, many authors include this tier under the heading of macro-economic decision-making (Caplan 1992). It is at this level that decisions regarding the allocation of resources among the various health care sectors is reached. Again there may be disagreement regarding the budget allocation between, for example, primary and acute care sectors. However ultimately, because the health budget is finite, resources at the meso economic level are also finite. Again contributions from professional bodies and both professional and patient pressure groups may have an impact on discussions and negotiations at this level. Recognition of the importance of negotiation at this level, in terms of the resources for nursing care, may lead one to suggest the need for nurses to develop specific skills in order to enable them to articulate more effectively not only the health but also the economic impact of nursing care. In order to be equipped to participate in these debates it would benefit nurses to be educated in the concepts, ideas and approaches to resource allocation and rationing. This middle level of resource allocation decision-making seems particularly important. It is the potential meeting ground for negotiation between those who come from a top down (government) and bottom up (grassroots practitioners) approach to resource allocation.

The micro economic level deals with allocation of resources at the day-to-day operational level. An example of this level of allocation is the posting of the three agency staff available to the hospital to the acute surgical units instead of the ED, on the basis of explicit, urgent need. Nurses tend to be acutely aware of the stresses and demands on resources at this level because it affects their everyday clinical practice. For example, if there is a linen shortage micro allocation decisions concern which patients get fresh linen. If two patients are demanding the attention of the only staff nurse on duty, ideally micro allocation decisions determine how the needs of these patients, balanced against each other and against the needs of the other patients on that particular unit, will be met.

These issues raise questions about the distribution of available resources. This is where rationing and resource allocation are directly linked and directly impact on the provision of care. Rationing is also about the distribution of available resources. However, deciding to ration resource X is based on acceptance that resource X is scarce – i.e. there is not enough of the particular resource to go around. Given conditions of scarcity how does one distribute that which is available? The underlying principle here is normally assumed to be that of ensuring the best outcomes given the context. This is known as the Utility Principle[2]. It is driven by the analogy of the battlefield and the notion of triage. Jonsen (1998, p. 2) suggests that;

> Triage (which means choice or selection) is required when many patients simultaneously need medical attention and medical personnel cannot attend to all at the same time, such as in a disaster or in the crowded emergency department of an urban hospital... the common sense rule is to serve persons whose conditions require immediate attention and, if this attention is not given, will progress to a more serious state. Others whose conditions are not so serious and who are stable, may be deferred.
>
> A second sort of triage is indicated in disasters, such as earthquakes, or in military action. The rules of military triage, developed centuries ago, direct the physician to attend first to those who can be quickly and successfully treated in view of a speedy return to the battlefield, or to treat commanders before troops in order to assure leadership. ... Disaster triage implies that the most seriously injured may be relegated to the end of the line and left untreated, even at the risk of death, if their care would absorb so much time and attention that the work of rescue would be compromised.

In summary rationing of particular elements of health care (a) assumes that there is not enough of the particular resource (or funding to buy it) for all who require and (b) that in these conditions of scarcity decisions have to be made regarding how this scarce resource should be distributed. The principle of utility (maximising benefit over burden) is often used to try to determine best use of the scarce resource.

Supply and Demand

However, regardless of who is using the health service or who is getting the most benefit from it, demand seems to be in constant danger of outstripping supply.

In Ireland, the imposition of austerity measures, including those from the European Union- International Monetary Fund (EU-IMF)[3] (2010–2013) led the Irish government to cut the health service budget by approximately 30% and remove

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[2] Please see Chap. 3 of this text for an introduction to Utilitarianism. Utilitarianism is a single principle theory. That single principle is the Principle of Utility.

[3] Ireland applied for a "bail-out" programme from the EU-IMF in 2008 in order to try to put public finances back on a sustainable path post the international financial crash in 2008. In November 2010 the Irish government agreed to what was widely considered the very harsh terms of the EU-IMF programme of financial support. Ireland exited this EU-IMF programme in December 2013, however it continued to be subject to twice yearly post-programme surveillance.

5,000 front line nursing and midwifery staff over a five year period. Many would argue that this has left a traditionally under-resourced health system unable to cope with day-to-day demand on the service. In effect austerity has meant significant rationing has been imposed across the Irish health service. However, no attempt has been made either by government or health sector leaders to name this reality. In fact successive Ministers of Health, from 2007–2014, have asked the Health Service Executive (HSE) to "maintain the same level of service" but significantly cut funding year on year; in the context of a rising population, changing demographics, and increasing demand (DoH 2014a).

Currently there are significant problems with access to required care, escalating waiting lists for elective surgery and increasing delays in accessing required diagnostic tests (Irish Times 2016a) and treatments (Irish Times 2016b), increasing complaints and investigations of poor and/or negligent care (HIQA 2013, 2015; DoH 2014b), and acute difficulties in recruiting and retaining nursing staff (INMO 2013; Health Sector Jobs 2016). In other words there is no spare capacity in the system; nurses report that care is deteriorating (Scott et al. 2013) as staff struggle to meet day-to-day patient care demands and patient safety is increasingly at risk.

In the absence of any informed debate about the appropriate allocation of resources, and the potential need to ration care (including nursing care) in certain areas, decisions regarding health care expenditure have little, if any, considered public input and are at continuous risk of being decided on the whim of individuals - individual medical and nursing clinicians, service managers, politicians and pressure groups. In this situation the risks to fairness of distribution and ultimately to patient safety are significant.

Into this mix can be added other factors which impact on, and potentially distort, health care resource expenditure decisions – for example the impact of marketing of pharmaceuticals and the latest diagnostic "kit". The impact of this "publicity bias" is described by Barilan (2015) as follows:

> We are bombarded by messages on the value of prescription drugs for health and happiness, while nobody promotes the importance of the time a nurse or doctor spends with a single patient or the value of foot care for the diabetic patient. … thus despite a tradition that values personal care for the sick, a growing number of patients are prescribed expensive medical services but cannot have somebody to listen to them properly and to help them wash, and eat. The publicity bias shifts everybody's attention (i.e. public, patients, clinicians, providers, advocates) from the very essence of care as an interpersonal event to commodified care and even more powerfully to commercialised services. We are driven to spend less on the basic and absolutely necessary and to feel more obliged to the market. Consequently we shift our priorities towards the less needed and more-preference-sensitive aspects of care." (p. 155–156)

These are profoundly pertinent words when one considers the findings of Francis (2010, 2013), Vale of Leven (2014), HIQA (2013, 2015) and DoH (2014b). In the tragic cases investigated by the Health Information and Quality Authority (HIQA 2013) and the Department of Health (DoH 2014b) in Ireland the report authors made the following statements:

> The Authority identified, through a review of Savita Halappanavar's healthcare record, a number of missed opportunities which, had they been identified and acted upon, may have potentially changed the outcome of her care. For example, following the rupture of her membranes, four-hourly observations including temperature, heart rate, respiration and blood pressure did not appear to have been carried out at the required intervals. At the various stages when these observations were carried out, the consultant obstetrician, non-consultant hospital doctors (NCHDs) and midwives/nurses caring for Savita Halappanavar did not appear to act in a timely way in response to the indications of her clinical deterioration. In summary, of the care provided there was a:
>
> - general lack of provision of basic, fundamental care, for example, not following up on blood tests as identified in the case of Savita Halappanavar
> - failure to recognise that Savita Halappanavar was at risk of clinical deterioration
> - failure to act or escalate concerns to an appropriately qualified clinician when Savita Halappanavar was showing the signs of clinical deterioration.
>
> The consultant, non-consultant hospital doctors (NCHDs) and midwifery/nursing staff were responsible and accountable for ensuring that Savita Halappanavar received the right care at the right time. However, this did not happen. HIQA (2013, p. 10)
>
> The overall conclusions in the Report are as follows: 1. Families and patients were treated in a poor and, at times, appalling manner with limited respect, kindness, courtesy and consideration. 2. Information that should have been given to families was withheld for no justifiable reason. 3. Poor outcomes that could likely have been prevented were identified and known by the hospital but not adequately and satisfactorily acted upon. DoH (2014b, p. 8–11)

However the Chief Medical Officer in the latter report does point out that:

> In order to fairly hold people to account, then we must ensure that they have the tools, capabilities, authority and supports they need to be accountable. It is simply not good enough for the system to place people into such difficult and challenging roles without also putting in place the sustained supports they require to carry out their responsibilities. DoH (2014b, p. 53)

It appears that greater focus on the nursing, midwifery and medical staff who deliver our services, including their number, leadership and the other supports they require, could have significantly improved the care the patients in all of these contexts received, and significantly reduced detrimental lack of care. However staff, while being the key health service resource, also bring costs – salaries, continuing education, and, more significant still, pension costs. Therefore if managers are being forced to focus only on the "financial bottom line" (HIQA 2012; Francis 2010) the clearest and most efficient way to reduce expenditure quickly is to cut staffing, Cuts in staffing, particularly nurse staffing, is a common response of health service managers in both Ireland and the UK – whether it be forced reductions in qualified staff and / or reduction in training places for student nurse and midwives – both of which have happened in recent years in the Irish and UK health systems (WIN 2016; Buchan and Seccombe 2012). The need to explicitly articulate and consider the impact of these decisions is now clear. Such clarity should help health service leaders and governments seek informed and public debate about health care priorities, resource allocation and rationing. However this will only happen if there is political, public and professional will to do so.

Resource Allocation and Nursing (Including Case Study)

It seems that when one is considering the nursing resource what one is considering is nursing time, and skill-set, spread across activities such as the following:

- physical care involving varying degrees of skill
- organisation of care
- co-ordination of patient care - with other practitioners and organisations
- patient monitoring, including practitioner insight into the patient's perspective of his or her need and goal
- psycho-social care and support
- trust and supportive presence - a journeying with
- patient education and preparation for discharge

The specific amount of each one of these which goes into the individual patient-nurse interaction will depend partly on the patient, and his or her needs and wishes, and partly on the professional insight or discretion of the nurse.

Recent inquiries (Francis 2010, 2013; Vale of Leven 2014; DoH 2014b; HIQA 2015) and empirical studies (Ausserhofer et al. 2014; Ball et al. 2013; Scott et al. 2013) all suggest significant restriction, in fact covert rationing of the nursing resource. Ausserhoffer et al. (2014) Ball et al. (2013) and Scott et al. (2013) all report that the nurses they surveyed, in acute medical and surgical units in hospitals across Europe, reported leaving care undone at the end of the shift; as a result of not having enough time to carry out all the patient care required.

Decisions regarding what care to carry out and what care to leave undone, unless explicitly discussed and agreed upon at a unit or ward management level, are covert rationing decisions. Covert rationing of nursing care in this way is potentially detrimental to the care and experience of the patients who are not receiving the appropriate nursing care. It is also potentially dangerous as it is not open to peer review or scrutiny. The fact that such covert rationing is not open to peer review and scrutiny, and is not openly discussed with either patients or the general public, also suggests that there are significant risks of unfairness - as such covert rationing is based on the judgements and biases of the individual nurse. Much of this covert rationing may go unnoticed by nurse managers and unreported by either nursing staff or patients – the latter may feel too vulnerable to do so, or may not realise they have a right to a good standard of care and a right to complain when this is not provided for them.

The contexts that have given rise to the more notorious cases of neglect and poor care (Francis 2010; HIQA 2013, 2015) are possibly at the extreme end of an erosion of nursing care, brought about by the recession and the severe pressures on health care and nursing staff. However this context of scarcity, unless challenged and ameliorated may lead to a longer term undermining of good nursing and thus good patient care; resulting in sub-optimal care becoming the norm, rather than something to be avoided. A recent example of the treatment of an inpatient on a medical ward of an acute general hospital in Ireland may help focus our discussion.

Mr D, a patient with a chronic neurological condition was transferred from the Intensive Care Unit (ICU) 12 hours post ventilation. A member of his family remained with Mr D from around 8 am to 10 pm as Mr D's neurological condition had resulted in significant memory impairment and an inability to transfer from short-term to long term memory. His family wished to ensure Mr D did not become distressed about his hospitalisation and his inability to recall his admission and so forth. Mr D was also on a significant amount of medication and assistance was required to ensure he got his medication on time and that Mr D actually took all the medication. No member of nursing staff came to visit Mr D, monitor his condition, or speak with any member of his family in the 18 hours the family was present in the ward to which Mr D had been transferred from ICU. One of his sisters, herself a qualified nurse, attested to this reality during the 8 hours she spent with her brother. In frustration at the lack of care, and following discussion with Mr D's consultant, Mr D's sister arranged for his discharge to her care.

It could be suggested that this case is an example of outright neglect of a vulnerable patient. It may be the result of an explicit or implicit decision to ration care to Mr D (as his family were known to be present and thus could alert nursing staff if a problem arose). Mr D's case does seem to be a case of outright neglect. However this is the type of situation that can arise when implicit rationing of nursing care is at play. Because decisions about the rationing of nursing time and care are implicit, they are not open to peer scrutiny, review or challenge. Both Alice and Mr D, it could be argued, suffered from neglect by nursing staff. Their care was clearly suboptimal at best and in Mr D's case nursing care was non-existent. There is a significant lesson here: if we start from a position that we have to ration care, and then do not make sure that our decisions on rationing are articulated, informed and made according to an explicit and agreed set of criteria, we face at least three significant risks:

1. There is a significant risk of unnecessary patient neglect and possible death (Francis 2010; HIQA 2013, 2015).
2. We risk eroding a model of good care as the norm for nursing care provision and nursing staff's expectation that this is the care they can and should provide.
3. We risk undermining the trust and respect the general public have for nurses and the nursing profession – there is already significant evidence in Ireland and the UK that this is happening and gathering pace.

In the studies by Auserhoffer et al. (2014), Ball et al. (2013) and Scott et al. (2013) a consistent pattern of nursing care left undone emerges across Europe. While physical care activities such as patient observations and medication were consistently carried out patient hygiene, comfort care, patient education and discharge planning, as well as documentation of care, were frequently and consistently among the care activities left undone. Such a pattern portrays a "hollowed out" notion of nursing care that is extraordinarily limited in its conception of such care.

This largely invisible, unaccounted for rationing of nursing care is likely to undermine the core of nursing and those elements of nursing care that patients place much value on – a supportive presence, comfort care, patient education, information about their condition, and medication, what to do when the patient goes home. There is an individual and a collective responsibility to challenge the provision of a reduced, rationed version of nursing care, in the name of good nursing, of patient safety and humane, ethically appropriate patient care.

Conclusion

It is essential that nurses, health service managers and the general public recognise nursing as valuable in patient care and therefore a resource to be treated with consideration at macro, meso and micro allocation levels. Nurses should explicitly and consistently discuss the perceived need to make rationing of care decisions with their managers and patients, in order that such decisions are scrutinised, challenged and, where necessary, explicitly articulated to the Director of Nursing, the Hospital CEO and the Board of Directors. Allocation of the nursing resource is overseen by ward managers / charge nurses on a daily basis across nursing shifts. Nurses then have considerable discretion regarding how their time is allocated to the care activities they engage in with the patients under their care. It seems important, on the basis of the evidence and arguments offered in this chapter, that explicit discussion around this allocation of the care time of the individual nurse, to her/his patients, be encouraged. In order to do so more effectively and to identify and discuss actual conditions of scarcity, and the consequent need to ration nursing care, nurses and their managers need to be educated in the principles and concepts of resource allocation and rationing. They also need to be educated to observe for, and monitor the effects of, both implicit and explicit rationing of nursing care.

Key Learning Points

- Resource allocation refers to the distribution of available resources.
- Rationing assumes that one is existing in conditions of scarcity and thus there is not enough of the required resource to meet existing needs.
- Rationing decisions should be explicit and open to scrutiny, review and challenge.
- Implicit (covert) rationing of nursing care is detrimental to good patient care. It potentially normalises sub-optimal approaches to nursing care and erodes public trust in the nursing profession.
- Health service and nursing leadership, as well as nurses themselves, should treat nursing time as an important health care resource to be allocated with careful consideration.

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Values-Based Nursing and Fitness to Practice Issues

13

Julie-Ann Hayes

Abstract

Values are often viewed as a reflection of moral, personal and cultural beliefs. Yet nurses are challenged with the additional consideration of professional values. In the United Kingdom (UK) the values that underpin the profession are articulated within the regulatory guidance from the Nursing and Midwifery Council (NMC). This guidance is a measurable tool of both practice and behaviour and falling short of this standard raises the question of fitness to practice.

This chapter explores the importance of values and how these values not only underpin practice, but determine fitness to Practice.

Keywords

Values • Morals • Professionalism • Fitness to Practice • Standards • Trust

Introduction (Including Case Study)

This chapter will explore the personal and professional values that we utilise within nursing practice. The chapter will draw upon healthcare values applied across healthcare practice and not only within nursing. A case study will allow us to explore these values in a nursing context.

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P.A. Scott (ed.), *Key Concepts and Issues in Nursing Ethics*,
DOI 10.1007/978-3-319-49250-6_13

Case Study

Joanne is in the 3rd year of her nursing programme of study. She is finding it difficult to balance her current workload and is struggling to complete her academic assessments within the deadlines. However, she is flourishing within the clinical environment and has received positive verbal feedback regarding her performance. On her final day of placement she is distracted by her workload and forgets to ask her mentor to complete some of her practice documents that state she is competent to undertake key skills. Later when she realises she has failed to complete the documents she contacts her mentor but the mentor is no longer on shift.

Joanne has an assignment to complete in the next 48 hours and the practice documents also need to be completed and submitted then too. Knowing that she would not have time to return to the placement area and complete the assignment on time she signs the document herself, feeling confident that if she had been able to get it signed they would agree she was competent and had suggested so in their verbal feedback to her.

Joanne submits the assessment and the practice documents on time.

What Is Value-Based Nursing?

Values are an important aspect of nursing and have received a huge amount of attention and emphasis in recent debate and discussion regarding healthcare and the drive to ensure that nurses possess the 'right' values. It is crucial to ensure that we understand what values are before we begin to attempt to 'measure' their existence in a workforce such as nursing. Developing a successful workforce depends on providing the necessary skills, behaviours and values, as set out in the 2015 review by Lord Willis, *Raising the bar - Shape of caring; a review of the future education and training of registered nurses and care assistants* (Health Education England 2015). Skills are measureable activities through competences and agreed frameworks, however behaviour and values are less tangible in their scope to be benchmarked.

Understanding the concept of values is an important starting point. Horton et al. (2007, p. 722) suggested that '*Values are what are important, worthwhile and worth striving for.*' Horton et al place 'worth' at the centre of their definition of values and indicate that values have both importance and an aspirational quality. Horton et al. (2007, p. 722) provide further, more detailed, understanding of the concept by highlighting that *'Values determine a person's beliefs and actions… values direct the priorities we live by and shape our being in the world'*. However we can explore this concept further by considering terms that are used in relation to values in nursing. The Table 13.1, adapted from Horton et al. (2007), lists terms that are frequently used when discussing values in nursing and illustrates that values are often assumed to be the origins of social behaviour.

Table 13.1 Frequently used terms relating to values

Responsibility	Compassion
Honesty/Truth	Caring
Dignity	Altruism
Autonomy	Competence
Nurturing	Trust/Trustworthy
Integrity	Empowering
Privacy	Morals
Courage	Judgment

Adapted from Horton et al. (2007)

These values are reflective of the six fundamental virtues necessary in nursing as asserted by Beauchamp and Childress (2013, p. 33–44) who suggested the following;

- Care
- Compassion
- Discernment
- Trustiness
- Integrity
- Conscientiousness

The terms that emerge through the work of Beauchamp and Childress (2013) and Horton et al. (2007) are mirrored within other literature (Hawley 2007; Baillie and Black 2015).

Moral and Personal Values

Moral values have an important influence on the approach that nurses adopt, the way in which they think and act, and consequently the care they deliver[1]. Jormsri et al. (2005, p. 586) suggest *'Morals are an individual's application of values'*. However, Horton et al. (2007) defines morals as the distinction between good and bad or right and wrong and highlights that the terms morals and values are frequently used in conjunction with each other. If moral behaviour then (i.e. acting on the distinction between good and bad, right and wrong, for example) are reflective of our values, then consideration of our values is crucially important.

If our personal values and beliefs influence our thinking, attitudes to people, and situations, and thus also influence our behaviours, this is a significant issue when we consider our professional roles as nurses. Of course it is essential to recognise that we are human beings first and foremost, and secondly we are professionals. However one of our aims as professional nurses is to enhance the nurse-patient caring relationship, as the important means through which we deliver good quality care, while respecting patient's ethical values and beliefs[2].

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[1] For further discussion of moral values in nursing and the ethical domain of nursing practice please see Chap. 1.

[2] For further description and discussion of the nurse patient relationship please see Chap. 1.

Conflicting Values

Values can influence our ethical decision-making, and for nurses values influence our perspectives on the delivery of patient care. However, conflict may occur between professional and personal values and present the nurse with complex challenges. For example we may personally feel it is acceptable to tell a lie in certain circumstances and yet in our professional roles honesty is viewed as paramount and the cornerstone of trust in the nurse-patient relationship.[3] Understanding professional values is crucial to equipping nurses with the skills and knowledge in dealing with these conflicting values.

Professional Values

Professional values can be viewed as the tools which enable you to become a morally sensitive practitioner. The values of the profession are captured not only in codes of practice such as within the Nursing and Midwifery Council (NMC) code of conduct (2015a) but are also articulated within the English health care context, through the Department of Health publication 'Compassion in Practice: Nursing, Midwifery and Care Staff: Our Vision and Strategy (DoH 2012)'. This work outlines what is believed to be the six core values that underpin health and social care. These values are branded as the 6cs of caring;

- Care
- Compassion
- Competence
- Communication
- Courage
- Commitment

These values are not dissimilar to those personal virtues articulated by Beauchamp and Childress (2013, p. 33–44).

Three of the core values identified within the DoH (2012) guidance are relevant when we consider the case of Joanne. The values that raise some concerns are competence, courage and communication. If communication is central to a trusting and caring relationship with our patients, and an effective and successful relationship with our colleagues, then the cornerstone to all communication needs to that of honesty and integrity. Joanne is presented with the challenge of communicating her situation to staff in both the university and the clinical setting or falsifying the records. Honesty and integrity in this situation would require Joanne to openly acknowledge her failure to complete essential documentation which may result in a delay in completing the assessment. This acknowledgement of her failure also

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[3] For further discussion of lying and honesty within the context of nursing and duty-based ethical theory please see Chap. 2.

indicates a requirement for Joanne to show courage, as being late with her assignment will have potentially serious implication for her ability to progress through her programme successfully and within the required time frame. Joanne makes the decision to falsify the document – indicating a lack of courage, honesty, and integrity. Having integrity is an essential aspect of good character and is considered to be a desirable quality in the nursing profession. Laabs (2011) describes integrity in terms of being a certain kind of person who is honest and trustworthy, consistently does the right thing, and is able to stand up for what is right despite the consequences.

Values of the NHS

Following the Francis Inquiry (Francis 2013) there has been an increased emphasis on values within the NHS. The NHS Constitution (DoH 2015) clearly outlines the rights and responsibilities for patients and staff. It identifies its core values as: respect and dignity, quality of care, compassion, improving lives, and working together.

The Francis Inquiry (2013, p. 1399) suggested that the NHS Constitution was a source of values and principles and stated '*All staff should be required to commit to abiding by its values and principles*'. This suggests that NHS staff should have an understanding of the values and principles required for caring for patients. The NMC (2015a) also stipulates the standards (values) required of registered and student practitioners.

When we consider an individual case such as Joanne it is important to remember that the broad ideas of the NHS Constitution (DoH 2015) are reflective of the 6C's (DoH 2012). Care, Compassion, Competence, Communication, Courage, and Commitment are relevant to every individual case and nurse. Joanne is required to deliver a high quality of nursing care and to demonstrate this through her assessed competence, compassion and commitment. The latter, i.e. commitment, may, on occasion, also demand the personal characteristic of courage – for example in advocating for a patient[4] or reporting inappropriate or inadequate care. Demonstration of competence to practice underlies the notion of being fit to practice. That is, being deemed worthy of a licence to practice as a nurse that is enshrined in the nurse's registration, with the national body responsible for nurse registration – in the UK this is the NMC.

Professionalism

Professionalism is the term most frequently used in relation to aspects of behaviour that relate to fitness to practice. Professionalism is defined in a variety of ways, and could include aspects of character and ethical behaviour, as well as skill and

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[4] For a discussion of the nurse's role in advocating for patients please see Chap. 8.

competence (Boak et al. 2012). The NMC (2015a) advises that standards of professional behaviour are based on the code of conduct. This informs the practitioner and the student that good character forms the foundation of professionalism. The structures in place to measure the professional standards of nurses are that of '*fitness to practice'*. We therefore may find ourselves asking the question 'Is professionalism and fitness to practice the same thing'?

Arguably professionalism is concerned with high standards and the best aspired to behaviour. In contrast fitness to practice is concerned with maintaining the minimum standards required for safe practice. Understanding the concept of fitness to practice as well as the relevant processes, however, may inform our understanding of how the regulatory body, in England this is the NMC, view and consider professional conduct and professionalism.

Understanding Fitness to Practice

Health and Social Care professionals are often subject to scrutiny regarding their practice and their professional conduct. The lens of that scrutiny is not only fellow professionals but also public concern. This is reflected in investigations of high profile incidents of patient harm, which involve health and social care professionals, such as the Clothier (Beverley Allit) Report (1994) and more recently the Francis Inquiry (2013). The resultant inquiries have recommended the need for effective professional regulation of health and social care professionals and reform across health care professions. Such inquiries have also formed the basis for changes in the regulation and the concept of fitness to practice (FtP).

In the United Kingdom the nursing profession is regulated by the Nursing and Midwifery Council (NMC). This body has both regulatory and statutory powers and came into force in 2002. One of its key functions is regulation. Professional regulation is achieved through a process of fitness to practice (FtP) which is defined by the Nursing and Midwifery Council (NMC) as

> *Being fit to practice requires a nurse or midwife to have the skills, knowledge, good health and good character to do their job safely and effectively* (NMC 2015b, p. 7)

The Nursing and Midwifery Council (NMC) came into force following the introduction of Project 2000 and the significant educational changes within the nursing profession which led to the replacement of its predecessor the United Kingdom Central Council for Nursing, Midwifery and Health (UKCC). The UKCC was set up in 1983 and had the function of maintaining a register of nurses, midwives and health visitors in the UK in addition to management of professional misconduct. The NMC continues with this structure for regulation and provides clear guidance regarding best practice for nurses and midwives. The most recent advice is via the NMC (2015a) Code of Conduct. This guidance includes defining professional standards and what constitutes "fit for practice". A referral to the NMC is a concern or complaint that is reported to the NMC. The concerns can be

Table 13.2 Types of allegations 2013–2014 and 2014–2015

Type of allegations	Percentage of allegations 2013–2014	Percentage of allegations 2014–2015
Misconduct	75%	80%
Criminal	15%	11%
Lack of Competence	6%	5%
Health	3%	3%
Fraudulent/incorrect entry to NMC register	Less than 1%	Less than 1%
Determination by another body	Less than 1%	Less than 1%
Total	**100%**	**100%**

Data from NMC (2014–2015) Fitness to Practice Annual Report (2015b)

raised against the registered practitioner, by an employer, a colleague, or a member of the public. During 2014–2015 the Nursing and Midwifery Council received a total of 5,183 new referrals in comparison to 4,687 new referrals during 2013–2014. Of the 5,183 of the new referrals 1,835 did not progress to panel (NMC 2015b). This means that although concerns were raised these did not warrant escalation to a panel. This decision is made through the process of an investigation that gathers evidence surrounding the concerns raised. However, the figures suggest that 3,338 new referrals were escalated to a panel. The main types of allegations that proceed to panels are categorized into six areas of concerns. These are illustrated in the Table 13.2 which also provides comparisons with 2013–2014 figures.

These figures indicate an increase in the number of FtP cases concerning misconduct of 5 percentage points However a decrease of 4 percentage points can be seen in the number criminal cases and a decrease of 1 percentage point in the cases surrounding lack of competence.

Determination of Fitness to Practice for registered practitioners is agreed by the NMC.

The NMC Fitness to Practice Panel hears evidence regarding alleged poor practice of both midwives and nurses, but they do not regulate pre-registration student nurses or midwives (i.e. those undertaking their training). The responsibility regarding regulation of students lies with the Higher Education Institution. As part of a contractual agreement with professional bodies, Higher Education Institutions (HEI) are required to monitor good health, character, discipline, standards of conduct, and performance throughout all pre-registration/qualification programmes and other programmes leading to professional qualifications. This includes monitoring such issues as occupational health checks and criminal record disclosure and self-declaration of good health and character.

Several other functional aspects of the NMC include:

- Maintaining a register- this includes a register which can be accessed by the profession and by the public of all registered practitioners.
- Setting standards for practice - this involves a series of guidance documents appraising students and registered nurses of expected standards

- Setting standards for education - this involves agreeing and setting standards for education programmes
- Conducting research
- Advising the government on aspects of nursing and midwifery
- Determining fitness to practice of registered practitioners - this involves conducting investigations in to FtP

A number of the above functional aspects of the NMC are self-explanatory, however the concept of FtP requires some consideration.

What Does Fitness to Practice Actually Mean?

There is an expectation from the public that registered practitioners are fit to practice throughout their careers. The NMC suggest that being fit means that nurses have the skills, knowledge, good health and good character to do their jobs safely and effectively by adhering to principles of good practice set out by the NMC.

The NMC indicates however that it is not only our professional performance that is at issue in terms of fitness to practice. NMC also suggests that anything that we do that might have an impact on public safety or confidence in the profession may be subject to challenge. This suggests to the registered practitioner and the student practitioner that the expectations of conduct and behaviour apply not only to professional life, but also personal life.

The NMC (2010) define the conditions that constitute being unfit to practice:

- **Misconduct-**this considers behaviour that falls short of what is expected of a registered nurse
- **Lack of competence-**this considers lack of knowledge, skill, performance, or judgement
- **Character Issues-** this condition usually relates to criminal behaviour (such as convictions and cautions although can relate to issues such as honesty)
- **Poor Health-** This relates to long term serious physical and mental health conditions
- **Previous Finding-** this relates to findings by other health or social care regulators or other licensing bodies
- **Barring-** This includes the Safeguarding Vulnerable Groups Act 2006, the Safeguarding Vulnerable Groups (Northern Ireland) order of 2007 or the protection of Vulnerable Groups (Scotland)

Even with a definition of the concept of 'fitness to practice' from the NMC there are still aspects of FtP that leave the registered practitioner and student practitioner alike unsure of what is expected from the professional body, in terms of their conduct and performance. The Professional Standards Authority (previously Council for Healthcare Regulatory Excellence CHRE) is the independent body accountable to parliament that oversees the work of the regulators of healthcare, including the NMC. CHRE (2008) recognised this cloudy uncertainty surrounding FtP and provided the 'statement explaining the purpose of FtP'.

In order to ensure public confidence the process of dealing with fitness to practice needs to be transparent and open to ongoing audit and review. It could be argued that this is achieved through regulation of the regulators by the Professional Standards Authority. The NMC report all of its decisions to the Professional Standards Authority for Health and Social Care and they provide feedback on the decisions made by the various panels.

The NMC requires that registered and student nurses have 'character and health'. What equates to 'character and health' is derived from the two key documents: 'Character and health decision-making guidance' (NMC 2016) and 'The Code-Professional Standards of Practice and Behaviour for Nurses and Midwives' (2015a). Public trust in nurses, as well as in the regulation and accountability of the profession, is vital for an effective nurse-patient relationship. Core professional values must be upheld not only by those who are qualified but also by student nurses. The previous NMC (2010) guidance on professional conduct for nursing and midwifery, for students, stated *'Your personal life counts too!'*. It further outlines how personal life counts by stipulating that behaviour and conduct, both during the programme of study and in personal life, may impact on fitness to practice and ability to complete the programme, in addition to the willingness of the university to declare good health and good character for its students to become registered nurses. This guidance has since been replaced by the NMC (2015a) 'The Code- Professional standards of practice and behaviour for nurses and midwives' which is a set of standards for all nurses - both registered and student.

'Good' Character and Integrity

'Good' Character

The NMC (2010) defined good character as 'based on an individual's conduct, behaviour and attitude' including conduct in personal life. The assessment of good character also took into consideration criminal convictions. This guidance has since been replaced and HEI's are required to adhere to guidance set by the NMC (2016). HEIs are still required to carry out a disclosure check on all applicants. Once on a course of study, students must inform the HEI of any changes in their status. Sellman (2007) suggests that verifying the good character of the student is problematic for the HEI to do and that the 'assessment' of good character itself is too simplistic, is not actually reflective of good character, and is arguably based on assumptions regarding traits that are neither fixed nor static. Sellman's philosophical consideration of this concept of 'character' and indeed 'good' is a challenge to organisations such as the NMC (and other regulatory bodies) that attempt to assess these traits without providing guidance or instruction to HEIs on this moral assessment.

The Department of Health (2006) has recommended that there should be a common approach to the understanding of 'good' character across healthcare professions. The Council for Health Regulatory Excellence (CHRE) (2008) argued that this would ensure that students aspiring to join a healthcare profession would clearly understand what was required of them in order to demonstrate 'good' character. CHRE (2008) does not formally define the concept of good character, but they do seek instead to provide underlying principles. The concept of 'good' character is a 'dynamic' concept: it is enacted in relation to other people, it is located in the context of changing social norms, and it takes account of the ability to reflect on past actions and the development of insight into past conduct (CHRE 2008, p. 3). CHRE advises that the assessment of good character be in line with the core principles of: protection of the public, maintaining public confidence in a profession, *'acting in accordance with the standards of the profession'* and *'honesty and trustworthiness'*.

Assessment of 'good' character can be based on negative or positive features. For example, 'good' character can be the assessment that a candidate will not and has not acted in ways which will risk harm to the public, 'undermine public confidence', show an 'unwillingness to act in accordance with the standards of the profession', or 'act dishonesty' (CHRE 2008). Alternatively 'good' character can be assessed positively, as the possession of qualities such as: commitment to the well-being of others, justifying public confidence, acting according to professional standards, and being honest and trustworthy (CHRE 2008). However CHRE (2008) argues that it is important for regulators to be realistic about their ability to determine a person's 'good' character and states *'The regulators cannot assure that an individual possesses (positive character traits) only that given the evidence available it is not reasonable to believe the individual lacks them'*. CHRE (2008, p. 2–3).

Integrity

Having integrity is an essential aspect of good character and is considered to be a desirable quality in the professional. The concept of trust and integrity underpins the 'code' with the following statement

> You should uphold the reputation of your profession at all times. You should display a personal commitment to the standard of practice and behaviour set out in the code. You should be a model of integrity and leadership for others to aspire to. This should lead to trust and confidence NMC (2015a, p. 15)

It further instructs how that trust and confidence will be achieved with a number of directives such as upholding the reputation of the profession, upholding your position as a registered nurse, co-operating with investigations and audits, responding to complaints, and providing leadership to ensure people's wellbeing is protected.

These instructions are an attempt to outline to the practitioner how trust and confidence is achieved, rather than working on an assumption that a practitioner simply knows how to gain trust. We often transfer societal norms to our professional behaviour and integrity and trust may be one such example of this. The reality is that trust is a necessary condition of healthcare. The willingness of one party to rely on another to act in a certain way is gained through the practitioners actions, but also to some degree society expects that practitioners will act in a certain way (this is a condition of their licence to practice as a nurse). By fulfilling their role, as expected, the practitioner gains pubic trust and is seen as trustworthy. An example of this is veracity or truth-telling which is often used as a measure within the trust debate. Veracity is crucial to the trusting relationship between practitioners and their patients. Although traditionally professional 'codes' (such as the Hippocratic oath) have not explicitly referred to veracity, the more recent NMC code (2015a) has made reference to the approach advocated by Beauchamp and Childress (2013) of health practitioners dealing with patients openly and honestly, suggesting that adhering to these principles facilitates the development of a trusting relationship between the patient and practitioner. It is important to be aware of the differences between trust and trustworthiness. Being trustworthy provides no guarantee that the patient's trust is apportioned in a sound manner. Therefore even though systems of accountability and aims towards transparency (e.g. the NMC, 2015c, Duty of Candour guidance) are in place, if patients have a distrust of these systems then trust itself may be hard to establish. Providing detailed instructions of 'actions' or 'behaviour' that will move towards gaining trust is a massive step for the NMC (2016) and reflects insight into the consideration of what society wants and expects from its nurses (and student nurses). It is also an acknowledgement that trust is no longer assumed but needs to be gained.

The NMC (2010) student guidance, that defines 'good' character, also provides detailed guidance on behaviour and conduct. This includes guidance on issues such as aggressive, violent or threatening behaviour, cheating or plagiarising, criminal conviction or cautions, dishonesty, drug or alcohol misuse, health concerns, and persistent inappropriate attitude or behaviour. It clearly outlines to students what it considers unprofessional behaviour and defines this as;

> Breach of confidentiality, misuse of the internet and social networking sites, failure to keep appropriate professional or sexual boundaries, persistent rudeness to people, colleagues or others and finally unlawful discrimination NMC (2010, p. 3)

This guidance by the NMC has been replaced in 2015 by the new NMC code NMC (2015a). Now, each HEI is required to provide a code of conduct and a fitness to practice policy. Arguably with such explicit guidance it would be reasonable to suggest that there is no doubt on what is viewed as unprofessional behaviour. Yet David and Lee-Wolf (2010) suggests that uncertainty does exist. They highlight that new students often do not appreciate that 'misbehaviour' in their spare time can undermine public confidence in them and their profession and may endanger their career. David and Lee-Wolf (2010) also highlighted that one of the major perils appears to surround the use of social networking in the context of patients and colleagues contrary to explicit guidance by the NMC. It is clear that students cannot be held to the same standard as registered professionals, simply by the nature of their developmental ‘learning’ role and that feedback on their performance should not be isolated simply to their clinical and academic progression but also refer to their professional performance. David and Lee-Wolf (2010) asserts that developing professional behaviour occurs through a combination of information, education, role modelling and reflective practice. They further suggest that managing that development requires an acknowledgement that students are colleagues who are novices.

In the case of Joanne, the student nurse we met earlier in this chapter, the issue of professionalism is a developing rather than a fully formed concept. However, it is important to note that as a 3rd year student there would be an expectation of a greater understanding and application of the principles of professionalism. This lack of insight from a more senior learner would raise concerns of fitness to practice.

David and Lee-Wolf (2010) highlighted that there should be clear guidance of what is expected in terms of behaviour at each stage of the programme of study and that it is vital that the level of expectation reflects the student’s progress on the course and also the level at which the student is called to account. When considering professional behaviour this is approached in a developmental manner. David and Lee-Wolf (2010) provides an example of this approach suggesting that a first year student called in to account for their actions would be reminded of the requirements of professional behaviour and the significance of their actions. Should the activity continue a further discussion would follow, with a further reminder of why these actions would be considered unprofessional, and the student would be asked to reflect on their behaviour and possibly a warning issued. If the student repeats the activity in the second or third year then such actions would become less understandable and acceptable and this may proceed to a Fitness to Practice panel.

In the case of Joanne, a 3rd student nurse, this is the first issue raised and we can identify external pressures that could be seen as mitigation. However, it is important to consider that although this is the first issue raised, the serious nature of the concern warrants consideration with the student and the potential escalation to an FtP investigation. A lack of previous concerns should not automatically abolish the need for an investigation. The nature of the concerns should be the deciding factor.

These developmental concerns that are raised regarding student understanding of unprofessional conduct clearly do not exist for the registered practitioner. The NMC would consider that every registered practitioner has a fully formed understanding of the concept of professional conduct and the code of conduct outlines the requirements in practice. The NMC has a number of options at their disposal to deal with any falling short of the expected standards. These are:

1. Close case with no further action
2. Refer case for an Interim Order Hearing
3. Refer case to an Investigating Committee Panel
4. Refer case to a Conduct and Competence Committee
5. Refer case to the Health Committee

As stated above within the NMC (2015b) annual fitness report a total of 5,183 new referrals were received in comparison to 4,687 new referrals during

2013–2014. Of the 5,183 of the new referrals 1,835 did not progress to a panel. The remaining four options are captured in the Table 13.2 data, illustrating an increase in all 4 remaining options. These figures, illustrated in Table 13.2, signify an increase in cases that challenge the practice of registered nurses and their understanding of the concept of professional conduct and practice. The NMC within their 2014–2015 Fitness to Practice Annual Report provided no explanation for the increase in misconduct cases. The increase in misconduct cases correlates with the publication of the NMC (2014) '*Raising concerns- guidance for nurses and midwives*'. Therefore, this increase could be attributed to raising awareness of the expected standard of conduct for nurses.

Conclusion

This chapter examines values, both moral and professional values, for nursing practice. There are a number of expectations on nurses, both registered and student. The way in which nurses conduct themselves is what constitutes fitness to practice and this is a reflection of knowledge, skill, performance, and judgement. This is also a reflection of nurses' professionalism which is built on agreed and shared values.

Through the consideration of the case of Joanne, we can see a challenging situation. The values we hold as human beings may sometimes conflict with that of our professional bodies. Being part of a profession requires an acceptance of certain standards. Such standards not only reflect professional competency but, importantly, also reflect the professional values that underpin the profession. Joanne as a student nurse has agreed to abide by the standards determined by the NMC (2015a) code of conduct. The code clearly demands that practitioners 'act with honesty and integrity at all times' and this clearly applies to the context outlined within the case study. Therefore there is a reasonable challenge to the student's fitness to practice.

Having clearly defined professional values has a number of potential positive impacts; such as strengthening the nurse-patient relationship and gaining trust in the profession. If we are prepared to put aside these agreed standards, that capture the values of our profession, the result can only lead to the erosion of the trust that is central to the nurse-patient relationship.

Key Learning Points

- Value-based nursing is ensuring that values underpin care delivery.
- Our professional and personal values can differ, however there are common values that are transferable across both our personal and professional conduct.
- The NMC code of conduct (2015a) outlines values that underpin our practice and promote safe and effective care.

- Guidance from the Department of Health (2012) '*Compassion in Practice: Nursing, Midwifery and Care Staff: Our Vision and Strategy'* provides more detailed guidance for practitioners in recognising values that underpin practice.
- Fitness to practice simply means that nurses have the skills, knowledge, good health, and good character to do their jobs safely and effectively, by adhering to the principles of good practice set out by the NMC.
- Failure to adhere to the guidance, maintain the good character and values that underpin our practice, and promote safe and effective care can bring your fitness to practice into question.

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Ethical Principles in Healthcare Research

14

P. Anne Scott

Abstract

Ethical issues permeate the entire research process from the identification of the research question and selection of research participants, to dissemination of findings. This chapter identifies some of the historical influences informing the development of research ethics frameworks internationally. The author then moves to highlight some of the key ethical issues that need to be considered throughout the various elements of the research process. Some of the important principles underlying research ethics frameworks are identified and interpreted within the context of the research process.

Keywords

Nursing research • Research ethics • Respect for persons • Autonomy Beneficence • Informed consent

Introduction

Recognition of the need to regulate research on human beings can be traced back to reactions against the abuses associated with German and Japanese research during World War II. However as the twentieth century rolled out it was increasingly recognised that a number of abuses, in terms of research on human subjects,

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The original version of this chapter was published in Curtis EA, Drennan J (2013) Quantitative health research: issues and methods. Open University Press. © Reproduced with the kind permission of Open University Press. All rights reserved.

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P.A. Scott (ed.), *Key Concepts and Issues in Nursing Ethics*,
DOI 10.1007/978-3-319-49250-6_14

continued into the post-war period in both democratic and communist countries (Mason and McCall Smith 2010). Revelations during the Nuremburg Trails, for example, of the atrocities committed in the name of medical experimentation during World War II, combined with other twentieth century medical research scandals such as the Tuskegee Syphilis Study 1932–1927 (Adams 1996), the Willowbrook hepatitis studies (Krugman 1986) and the New Zealand cervical cancer inquiry (Cartwright 1988; Paterson 2010) has helped develop widespread resolve regarding the need to protect participants in human research projects and the need to continue to monitor the conduct of such research internationally. The first internationally accepted set of ethical guidelines with regard to these issues was the Nuremburg Code published in 1947 (for further comment see Annas and Grodin 1992). The World Medical Association (WMA) publicly endorsed the principles expressed in the Nuremburg Code by drawing up the Declaration of Helsinki in 1964 (WMA 1964). This Declaration has been revised a number of times since its first publication.

The past 30 years has seen a number of countries and organisations highlight issues surrounding the ethics of research on human subjects: for example the Belmont Principles (The Belmont Report 1979), the Irish Council for Bioethics (2004). In the nursing arena NMBI (the Nursing and Midwifery Board of Ireland) (2015) the Royal College of Nurses (RCN 2011) the International Council of Nurses (ICN 1996) and the Nordic Nurses Association (1995) all published new or revised guidelines for nursing research. Issues regarding the human rights of research participants have also been underlined by the Council of Europe (Council of Europe 1997).

Guided by international instruments (such as the Nuremberg Code, the United Nations Declaration on Human Rights (1948) the United Nations Convention on the Rights of the Child (1989), the Belmont Report (1979), and the Declaration of Helsinki (WMA 2008)), in addition to various ethical theories that have become influential in health care ethics in general, such as Kantian ethics and the principle-based framework of Beauchamp and Childress (2013), a conceptualisation of appropriate ways to treat and protect human beings, both the fully functioning adult and vulnerable human beings such as children, the older person, the terminally ill, has emerged and continues to be modified over time.

However as we move towards the end of the second decade of the twenty first century there are certain ethical principles that are seen as fundamental to the framework of ethics that guides decisions regarding the morally appropriate consideration and treatment of human being during research activities. For example the Irish Council of Bioethics in 2004 commented as follows:

> Research involving human participants should be based on a fundamental moral commitment to the individuals concerned and to advancing human welfare, knowledge and understanding. A number of guiding moral principles govern the ethical review of research proposals. These principles aim to protect the well-being and rights of research participants/volunteers. (p. 6).

Some Important Considerations

Human beings are deserving of respect and protection as inalienable rights (UNDHR 1948). This is equally the case during research activities as it is in any other circumstances. Based on the work of the philosopher Immanuel Kant[1] such values are expressed in the principle of respect for persons, sometimes translated as respect for autonomy. Such expressions of course raise questions of the definition of person and autonomy and when and in what set of circumstances such concepts are and are not applicable.[2] However for the purposes of this chapter we will take it that respect is applicable to all human participants in nursing and health care research. The question then arises regarding what this actually means in the case of individual participants in a particular research project. At a minimum, the considerations explored below are relevant.

Respect for the Human Person

Within the context of research activity the principle of respect for persons is frequently articulated in terms of rights – both rights to autonomous participation and welfare rights (welfare rights refer to the right to have one's support and protection needs respected). Some such rights are the following:

- The right not to be injured or mistreated.
- The right to give informed, un-coerced consent to participate in the particular piece of research.
- The right to privacy, confidentiality and/or anonymity.

In terms of protecting the participant's right not to be injured or mistreated, it is normally the duty of the research team not to expose the research participant to significantly burdensome, unreasonable, known or predictable risk. On occasion however, when significant burden or predictable material risk is unavoidable, it is the duty of the research team to provide appropriate information on the likely burden and /or risk involved, so that the participant can determine if they fully understand and accept such burden or risk. Thus, for example, in drug trials and trials involving medical devices, the trials are phased and normally commence with non-human (laboratory and animal) trials. Such measures help to provide insight into likely effects of the particular drug or device – at least on non-human subjects. Thus by the time clinical trials (trials using human participants) commence, previous phases give insight into the actions of the agent (drug or device for example). This provides a certain level of confidence that the agent will either not cause

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[1] For an introduction to Kantian ethics please see Chap. 2.

[2] For discussion of conceptions of personhood in nursing and ethics please see Chap. 6. For a discussion of the concept of autonomy please see Chap. 7.

significant physical risk to the trial participants or that any such risks, which will be explained to the participant prior to participation, can and will be managed and /or mitigated by the research team. Where discomfort, burden and/or risk cannot be avoided such discomfort, burden and/or risk must be proportionate to the anticipated gain, either directly to the individual participant and/or to humanity or society. Such considerations are directly linked to the discussion of the principles of beneficence and non-maleficence below.

Informed Consent

Respect for the individual's right to make decisions about themselves and their life (respect for autonomy) requires that research participants are adequately and properly informed regarding the nature of the research project. For example, potential participants must be informed with regards to what will be required of the individual participant, including the approximate time requirement, any procedures that will be performed on him/her, any known or predictable risks or side effects, the nature of the trial (where a clinical trial is part of the research design), whether a placebo is being used, whether the trial is blinded and so forth. Such information enables the potential research participant to give *informed consent* to participate in the particular research activity or project.

There are two other crucial elements that must be in play in order to ensure that consent is not only informed but also voluntary – and thus autonomously exercised. These elements are:

- The participant must have the capacity to both understand the information being provided regarding the particular piece of research, including the implications of participation for the individual, and the (cognitive) ability to exercise consent.
- The participant must be free from coercion. Thus the participant must be assured and accept, for example, that refusal to consent will not affect her/his current care and treatment if the individual is being cared for by any member of a health care team; either in hospital or in the community. The individual should also be free from any other form of duress related to the research in question - from the research or health care team or from relatives or significant others (see Doyal and Tobias (2001) for a detailed discussion of the principal requirements of informed consent).

In instances where the potential research participant is a patient, practitioners should be aware of the profound influence that they may have on patients to whom they suggest participating in research. For example Kass et al. (1996), in a study on participant consent to involvement in cancer clinical trials, express it thus:

> Clinicians should be mindful of the tremendous influence they have over their patients, given that the mere suggestion of enrolment in research by a patient's personal physician was interpreted by many patients to be endorsement.

Some research, within the context of health and developing the appropriate evidence base for health care provision, will require the participation of individuals who are incompetent or temporarily not competent to give consent to participate in the research activity. Such people should only be involved in research under very clearly articulated and strictly monitored conditions. If it is impossible to carry out the particular research project with competent participants (or for example to wait for the unconscious person to regain consciousness, or where such would invalidate the study) consent must be sought from the legally authorised guardian of the individual involved. As a general rule of thumb incompetent individuals, or members of other vulnerable groups, should only be involved in research when it is reasonable to expect that the individual, or the group of which she /he is a member, will ultimately benefit from the research in question; and where the potential participant is exposed to minimal risk and burden. This is part of protecting the welfare of such individuals. However it is also important, from an ethics point of view, that people with these kind of disabilities are involved in high quality research that is relevant to their care and treatment – in order to develop a relevant evidence base for this care and treatment.

Should the potential participant, identified as incompetent to consent, be able to give assent to participation in research, such assent should be sought - in addition to the consent of the legal guardian described above. In such circumstances a decision to withhold assent should be acknowledged and respected; thus this individual should not be included in the research project in question.

A corollary of informed consent is that the individual should be assured that her/his participation, responses, tissue samples and so forth are being used for the purposes of the identified research project only. Personal information and/or donated material, such as tissues samples, will then be destroyed under properly regulated mechanisms that are fully protective of the autonomy and privacy of the participant. If this is not the case the potential participant should be made aware, explicitly, that it is intended to use such material for another, future study or studies. This enables the potential participant to knowingly consent, or withhold consent, to any potential future study. It clearly protects against a recurrence of cases, such as those reported in the past in both Ireland and the UK (The Royal Liverpool Children's Inquiry Report 2001; The Dunn Inquiry 2005; Government of Ireland 2006), where human organs were retained, post mortem, for potential use in current or future research projects.

In some, perhaps many, nursing research projects private, intimate information may be sought from the research participant during data collection; for example, information on previous medical history, information on personal behaviours and habits or information on the participant's children, siblings and so forth. Intimate, personally significant information may also be discovered as a result of interventions designed into the particular research initiative –i.e. genetic screening, chromosome studies, screening for risk of cancer and cardiac disease, alcohol use, sexual activity, patient satisfaction surveys and so forth. Research participants, in order to be properly protected from unwarranted risk of such personal information becoming available publically, and thus potentially being used to the detriment of the research participant, (and to enable the participant to feel safe to participate in the particular study) should be assured that such *personal information will be kept private and confidential*. Where strict confidentiality cannot be assured appropriate mechanisms should be designed into the study to protect participants. Participants can thus be assured that their identity will not be divulged – i.e. the *data collection, handling and storage processes protects anonymity*. In this latter case, for example, participants are normally not asked to divulge their names on self-completed questionnaires– such as when completing patient satisfaction questionnaires or when a staff member completes a staff survey.

Beneficence and Non-maleficence

Two of the internationally accepted, fundamental core principles underpinning both nursing practice and research are the principle of beneficence (do good) and the mirror principle of non-maleficence (do not harm). Thus one should do good to and should not harm one's patients, clients or research participants. Clearly some interventions (for diagnostic, therapeutic and/or research purposes) may be uncomfortable, burdensome or painful. Some may cause a degree of harm - for example surgical intervention, dressing of wounds and burns and so forth. However, the basic stance is that the core function of the health care professional is to work for the benefit of the patient or client from a health perspective. Thus the practitioner or the researcher must not cause unnecessary or avoidable harm or distress to one's patients, clients or research participants. Article 6 of the Declaration of Helsinki states this position with particular clarity: *"In medical research involving human subjects, the well-being of the individual research subject must take precedence over all other interests"* (WMA 2008).

In order to continue to develop the evidence base for health care and nursing practice, relevant, well-designed research is both important and essential. Conversely, the results of poorly designed research may, at worst, seriously harm participants or, at best, waste their time, while at the same time make misleading or detrimental contributions to the evidence base. This means that significant time and effort should be invested into research training and research oversight and governance.

At the level of the individual participant the duty to do good, and prevent harm, warrants equal vigilance. In instances where the participant is likely to experience discomfort, burden and/or risk, such discomfort, burden and/or risk must be proportionate to the expected gain from the research study – either directly to the participant and/or to society as a whole. Within the context of clinical trials, particularly drug trials for example, this gives rise to a number of issues. In the first instance in order to warrant the use of a clinical trial there must be genuine doubt with regards to the efficacy of the drug, or treatment intervention being considered. This is often referred to as a state of *equipoise*. Such conditions exist when either the evidence is not available from which to make a judgement regarding the impact of a particular intervention, or in situations where that evidence that does exist is inconclusive and/or contradictory. (For a useful discussion of this concept in particular, and ethical issues underlying intervention studies in general, see O'Mathúna 2012).

As indicated above when moving to set up clinical trials the relevant groundwork must be completed and verified, prior to introducing human trials. Appropriate oversight of the trial including close monitoring of participant responses must be assured. Furthermore, when patients are participating in experimental drug trials they must be fully aware of this, including being made aware of the very high chance of the experimental intervention not "working". From the perspective of the ethical conduct of the clinical trial it is good ethical practice for the research team to have a protocol in place to help determine when participation in the trial should be terminated. Such a protocol is particularly pertinent in experimental trials of new anti-cancer agents. The lack of such a protocol can lead to unnecessary hardship for very ill, vulnerable patients and for the staff who care for such patients (for a detailed description and discussion of these and related issues see Hobson 2003).

A corollary of the principles of beneficence and non-maleficence, in terms of clinical trials, is that a study must be stopped immediately, when the risks are found to outweigh the potential benefits. A similar imperative exists when there is conclusive evidence of positive and beneficial results from one of the agents under investigation.

Justice (Including Case Study)

Within the context of research activity the principle of justice can be conceptualised as fairness (Rawls 1985). In Rawlsian terms fairness is achieved if the principles guiding distribution of capabilities and resources, for example, are applied so as to ensure that the "least advantaged" are benefitted and not harmed or forgotten. Thus research participants should be treated fairly. For example, if participants are being put at considerable discomfort, inconvenience or risk (it is assumed that participants are fully aware of the demands being made of them), then it may be completely reasonable to compensate a participant for such inconvenience and any expenses they may incur due to their participation in the particular research project. However such compensation should not be such as to induce financially vulnerable individuals to place themselves at significant risk for financial gain.

Another issue that emerges during discussion of the principle of justice, within the context of research activity, is who should participate in research activity? Should certain groups be excluded on grounds such as vulnerability? Over the past number of years it has been recognised that all patient /client groups, including those identified as especially vulnerable, have the right to participate in, indeed may be necessary participants in, investigations to improve health care and to generate a sound evidence base for such care. For example the 5th article of the Declaration of Helsinki (WMA 2008) states the following:

> Medical progress is based on research that ultimately must include studies involving human subjects. Populations that are underrepresented in medical research should be provided appropriate access to participation in research.

However article 17 qualifies this in the following manner:

> Medical research involving a disadvantaged or vulnerable population or community is only justified if the research is responsive to the health needs and priorities of this population or community and if there is a reasonable likelihood that this population or community stands to benefit from the results of the research.

Groups that come to mind are children, the terminally ill, those who are physically disabled or cognitively impaired. It is a matter of justice that such individuals are enabled to participate in relevant research as fully as possible. Such participation assists in developing our understanding of the health and illness experience of certain vulnerable groups. It helps gain insight into their perceptions of, responses to, and requirements of, interventions provided by health care practitioners (and the health service they encounter) over the course of their lives/illness trajectory.

However special considerations need to come into play to ensure appropriate support and protection of such individuals. In particular specific mechanisms must be put in place to ensure that the welfare rights of vulnerable groups are recognised and protected.

A relevant case example concerns emerging research interest in the use of a micro camera (SenseCam), to record daily life of individuals (life-logging) with early-stage dementia (Piasek 2015). *The research focuses on an in-depth analysis of the experiences of three people in early-stage dementia whilst using, over a 7 week period, an automatic camera taking photographs of the person's day-to-day life. Each participant had 14 contacts with the researcher over the 7 week period. The study is unusual in terms of the depth of analysis, and the opportunity it provides for the person with dementia, and in two of the cases a family care-giver, to voice their experience of taking part in a trial of a new, potentially therapeutic, intervention. The intervention is placed in the context of how a person with dementia might maintain his/her identity in a situation where cognitive impairment may make this increasingly difficult.*

This study is enabling much needed research on a potential treatment of a vulnerable group of people – those with early stage dementia. However in addition to key ethical issues regarding respect for persons and information giving to enable informed consent in this study, the study also generates a requirement to acknowledge that the intervention used may generate distress in either the person with early stage dementia or the carer - thus causing potential harm. This highlights the need to identify and put in place measures to be taken should distress occur. There are also potential ethical issues related to privacy – not only those of the participant and carer, but also issues of photographing unsuspecting members of the public, should the participant have the camera on and rolling, while entertaining guests in the participant's home or while out in public places.

Working It through: Ethical Issues and the Stages of the Research Process

As indicated above, ethical issues and considerations permeate the entire research process. This begins with the research questions that are asked (and that receive research grant funding as against those questions which do not get asked and those projects which, through lack of funding, do not proceed) and continues right through to reporting of research findings and terminating the researcher/ respondent contact.

Researchers need to be sensitive to the nature of particular research agendas and the motivations, personal, political, institutional and socio-cultural, that drive them. For example, the current drivers of evidence-based practice in health care are at least tripartite - political, economic and professional. As practitioners we are becoming more convinced that our practice must be evidence-based - and there are numerous clinical studies going on attempting to develop our evidence-base. However, it is interesting to note that we are a lot less clear on what we mean by evidence, or what should count as evidence in health care practice (Scott 2006).

It seems reasonably clear that what counts as evidence for X (health care practice for example) largely determines the type of evidence we should be seeking and the studies that should be funded. Despite this, little work is currently being carried out, or being funded, in relation to questions regarding the nature of the evidence base appropriate for healthcare and nursing practice. This problem has philosophical, moral and professional implications. One of the most serious is the potential impact that our lack of knowledge and understanding, regarding the nature of an appropriate evidence base, will have on patient care.

However, once the researcher has decided on the appropriate research question, it is a moral and professional requirement to ensure that the selected piece of research is necessary. Thus the researcher needs to be sure that the knowledge is required, and does not already exist in a sufficiently comprehensive state. This indicates the need for the researcher to be equipped to do the required literature searching and reviewing. To do otherwise is likely to lead not only to a poorly refined research question and consequent poor research design; it is also wasteful of resources and shows a lack of respect for the study respondents and those who provide support for the researcher.

Assuming that the research question is a legitimate and useful one, the researcher must draw on personal or outside expertise in designing an appropriate study, that will provide a real possibility of gaining answers to the research question posed; or which will provide a firm basis for further work. This is not only a methodological issue. Sound study design is required in order to ensure that the study is ethically sound. Lack of appropriate expertise in study design is again, at a minimum, wasteful of time and other resources and indicates a lack of respect for respondents and those supporting the work of the researcher. At worst such lack of expertise may be positively damaging to the research respondents. Given that nursing researchers frequently carry out research with respondents already made vulnerable through illness, as indicated in the short case example above on the potential therapeutic use of SenseCam, lack of appropriate expertise is particularly unacceptable from an ethical perspective.

Once the researcher is confident that the design of the study is appropriate and that the data collection methods/tools will obtain the data required, ethical considerations broadly focus on ensuring respect for the participants and include the following elements:

- The role of the practitioner-researcher and the implications of the researcher identifying him or herself as a nurse, doctor, physiotherapist, clinical psychologist and so forth. The implications are potentially both positive and negative. Such self-identification may make recruitment to a study much easier – both because it may provide easier access to a participant pool and /or because a health practitioner such as a nurse is automatically seen as trustworthy by a patient or member of the public. However, it may also confuse or set up false expectations in patient-participants. Conflicts of interest are likely to arise where a practitioner is using his/her own patient group in research. Such confusion of roles should normally be avoided. Where a self-identified, qualified practitioner is carrying out a piece of research (for postgraduate work for example), it should be made clear to a participant that the researcher is not responsible for the participant's care and refusal to participate in the research will not have any impact on care provision. This should also be expressed, clearly, on either the written information participants receive regarding the research study and /or on the consent form. In the case of vulnerable group – such as those cited in the case example above – the fact that the researcher is not responsible for the participant's health care, should be repeated on each visit to /contact with the participant.
- The balance of potential inconvenience or risk to participants over potential benefit to participants and/or others. For example with the life logging example described above, the potential to come up with what ultimately may prove a beneficial intervention for some people with dementia must be balanced against the potential to cause distress and anxiety to study participants in current, very early stage exploratory studies.
- Appropriate and sufficient information must be given regarding the nature of the study to enable the potential participant to make an informed choice, and to give or withhold informed, voluntary consent. Taking the example of the individual with dementia the researcher needs to think through, very carefully, what types of information should be provided to the participant (and perhaps also the main carer) and in what form(s) this information should be provided. People experiencing cognitive decline and memory impairment pose particular challenges to the meaning of "being informed" and "giving informed consent". In

the moment of engaging with the researcher, these individuals may understand clearly what the study is about and what is being asked of them as participants. They may also agree to participate very willingly in the proposed study. However this understanding and willingness to continue to participate will need to be reconfirmed on each occasion the researcher interacts with the participant.

In instances where the participants are unable to receive the information or to make informed decisions, for whatever reason, clear transparent processes which aim to ascertain and protect participants' interests, throughout the period of their participation, must be instituted. The continued right of competent participants to withdraw from the study, without any negative consequences to the participant, must be made clear at the commencement of the study and thereafter, as the study unfolds, as required.

- Issues of anonymity and confidentiality must be given careful consideration, and detailed information on these notions given to participants. As de Raeve (1996) points out this may be particularly pertinent for health practitioner/researchers who may, for example, be used to the rather broader notion of confidentiality which is used within the health care team.

In empirical studies, data collection is a crucial area for research ethics. Ethical issues can be identified in the following areas:

- Obtaining permission for data collection from the organisation in question.
- Obtaining permission for data collection from the participants (patients, professionals).
- Consideration of who else may need to be approached in term of permission – in the case example above visitors, friends or even members of the public exposed to the SenseCam camera should be informed of the study and be given the option not to be recorded when in the vicinity of the study participant.
- Guaranteeing appropriate ethical behaviour from researchers during the data collection period.

As discussed above, in obtaining permission from individual participants, the issue of informed consent is central. It should be noted that normally practitioners directly involved in care giving do not obtain participants' consent to participate in research, as clear conflict of interest issues may arise. However clinical nurses, in particular, may have a significant role in supporting patient–participants in making informed decisions regarding participation in a particular piece of research (NMBI 2015).

In line with the principle of respect for persons, participants' anonymity, confidentiality and willingness to participate must be ensured. Risks/benefits/burdens to respondents must be explored. The risk or burden to the participant must be weighed against the potential benefits of the research findings to the general population or specific patient populations. In the case example above this translates into the need to balance any potential for distress to be caused to the study participants and/or their carers' with the potential to identify a useful new therapy for certain individuals with dementia. Participants in clinical trials must be as fully informed as possible regarding the nature and objectives of the trial. It should be made clear to the participants the nature of any specific risks or benefits that may accrue to trial participants. As highlighted above in relation to individuals with some element of cognitive impairment, it is important to bear in mind that informed consent is an ongoing process. Research participants may have questions that arise during the data collection process, in particular, that should be addressed. Participants must also be informed and assured that they may withdraw their consent and cease participation at any point during the research process, without this negatively impacting on them or their care.

Ethics and Data Analysis

Analysis of data is an interesting issue from an ethical perspective. At a minimum the researcher and /or his or her research advisors need to have a good grasp of both the strengths and limitations of the method of analysis or any analytical tools used. This is important from an ethical perspective in order to ensure that no inappropriate claims are made, based on the analysis. The relevance of this point in terms of clinical practice and patient care is clear. A significant reason for carrying out empirical research, within health care, is to improve patient care and develop sound policy and practices. Inappropriate analysis is likely to lead to inaccurate results and thus potentially to poor policy and practice.

Ethics and the Relationship with Research Participants

de Raeve (1996) highlights the lack of attention to ethical issues surrounding 'leaving the field' or termination of the relationship between researcher and participant. This is likely to be a particularly complex issue for researchers involved in some forms of qualitative research and in some psycho/socially focused intervention trials. It was an issue in the SenseCam intervention study (Piasek 2015) described above. Study participants and the two carers involved had come to rely on the researcher for social interaction, the hope of effective treatment and, for one of the carers, the ability to get some time to themselves while the researcher was with the participant. A researcher needs to be aware of the potential problems in this type of researcher-participant relationship. Steps should be taken to ensure that the participant does not confuse the research relationship with a therapeutic, counselling-type relationship or a friendship. Insight and personal integrity is actively required from the researcher throughout the data collection period to guard against misuse or abuse of the researcher-participant relationship (O'Mathúna 2012).

Ethics and Dissemination of Research

From an ethics perspective, if the researcher is to value and respect the contributions made by participants, funding bodies and others supportive of the research effort, it is incumbent on the researcher to report and disseminate the findings of the particular study - positive and negative - in the most effective ways available to the researcher.

In reporting the study results, the ethical issues include continued protection of the rights of, and honouring promises made to, participants (e.g. confidentiality, protection of privacy, anonymity), reporting findings truthfully, accurately and completely, citing appropriately the work of others and ensuring the authorship credits and acknowledgements are stated accurately. To do otherwise once again indicates lack of respect for the various actors in the research process. It is also wasteful of valuable resources, including those of future researchers who might have gained from the sign-posting of "blind alleys" and from insights into the findings, strengths and weaknesses of the unreported study.

Conclusion

A number of the key ethical principles relevant to research with human participants are explored in this chapter. The ethical understanding thus gained is then applied to the component elements of the research process. High quality, ethically sound research is important in developing the evidence base for health care practice and in the provision of effective, humane patient care. Understanding the principles guiding ethically sound research activity is thus a key component in the education and practice of health care professionals.

Key Learning Points

- The need to ensure a strong ethical framework to scrutinise and regulate research in health care has been informed, in particular, by the abuses of World War II and a number of notorious research scandals uncovered in the twentieth century.
- Within the context of research the principle of respect for persons refers to ensuring, for example, that participants are adequately informed about the research project. Such information should enable participants to give informed consent to participate in the piece of research in question. Respect for persons also requires that participants are assured of confidentiality or anonymity and that their privacy is protected.
- Two other important ethical principles underlying ethical research practices are the principles of beneficence and non-maleficence: Literally this means, respectively, do good and do no harm. Within the research context participants should be adequately protected and researchers should avoid exposing participants to unnecessary and undue discomfort, burden or risk.

- The principle of justice demands that research participants should also be treated fairly. All sectors of the population including, where relevant, vulnerable groups and individuals, should be enabled to participate in research initiatives. Such participation requires additional protections to be in place.
- Ethical issues permeate the entire research process from question identification and selection to dissemination of findings.

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Clinical and Organisation Ethics: Implications for Healthcare Practice

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Abstract
Clinical and organisation ethics are relatively new forms of ethical governance in healthcare. Clinical ethics identifies and addresses ethical challenges arising in the clinical setting, while organisation ethics addresses ethical issues relating to the management and financial operation of healthcare institutions. The following discussion will examine each in turn.

Keywords
Clinical ethics • Organisation ethics • Ethical challenges • Ethics of healthcare

What Is Clinical Ethics?

Clinical ethics is an emerging discipline which provides a structured approach for addressing, analysing and, where possible, resolving ethical issues which arise in the clinical setting (Jonson et al. 2006, p. 1). Less an academic sub-discipline within bioethics than a form of practice which 'takes place' in the clinical setting, it emerged in response to new needs created by technological advances, increasing diversity in the patient population, and the growing complexity of clinical decision-making in an era of managed care (Shelton and Bjarnadottir 2008, p. 49).[1] Within healthcare organisations, clinical ethics support may take a number of forms, but the

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[1] For reasons of space, a discussion of managed care and its implications will not be included here.

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P.A. Scott (ed.), *Key Concepts and Issues in Nursing Ethics*,
DOI 10.1007/978-3-319-49250-6_15

general rationale for establishing a service of this kind is to "*provide health professionals, hospital administrators (and increasingly patients) with information, assistance and, where requested, guidance in relation to ethically-challenging situations arising in the course of healthcare delivery*" (Campbell and McCarthy 2017). Underpinning this rationale is a drive to improve both the quality of patient care and the process of providing care (ASBH 2011, p. 3; Fletcher and Siegler 1996, p. 125).

During the course of the past 30 years, clinical ethics has evolved from an innovative but ad hoc activity conducted on the fringes of healthcare provision to an *"organised and widely accepted healthcare service"*. (Fox et al. 2007, p. 13). As a form of practice, clinical ethics has matured more rapidly in Canada and the US than in Europe, largely because a formal mechanism for addressing ethical issues in clinical practice has been a requirement for the accreditation of larger hospitals in the US since 1992 and in Canada since 2002. The most common form of clinical ethics service is the committee model, which has become increasingly prevalent in the US, UK, and EU since the beginning of the twenty-first century,[2] although many large urban hospitals in North America currently employ individual consultants with specialty training in ethics. Unlike research ethics committees – which are mandated by law to review all clinical trials involving human participants – clinical ethics committees have no legal standing, and, consequently, no standardised operating procedures or role-specific responsibilities. Clinical ethics committees are multidisciplinary bodies whose membership includes medical, nursing, allied health and social care professionals, in addition to administrators, risk managers, ethicists, legal experts, and lay representatives. In addition to the inclusion of a broad diversity of perspectives, however, genuine multi-disciplinarity requires "*professional respect for the contribution of each member*", premised on an indifference to status within the organisation (Meijburg and ter Meulen 2001, p. 39i).

The Role of Clinical Ethics Support Services

The three accepted functions of clinical ethics services are to provide ethics education to hospital staff, executives, and administrators, to review and develop hospital policies with a focus on ethically-relevant issues, and – most controversially – to provide support, advice, or guidance in relation to active clinical cases where there is conflict or disagreement. Individual clinical ethics services balance these three responsibilities in different ways depending on the nature, size, and needs of the organisations they serve and on the role assigned to the service within the organisation (Hackler and Hester 2008, p. 18). While there is no 'blueprint' for ethics consultation, a central feature of the process is the use of a structured approach for analysing difficult cases which is based on accurate identification of the issue

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[2] These committees are known in the US and Canada as Health Care Ethics Committees (HCECs) and in the UK and Europe as Clinical Ethics Committees (CECs). The terms 'Clinical Ethics Service' (CES) or 'Clinical Ethics Support Service' (CESS) are increasingly used in the literature, and will be used in this chapter, to denote both.

involved and a robust method for gathering information. In 1986, Jonson, Siegler, and Winslade proposed a comprehensive framework for analysing ethically-challenging cases which was conceived as an alternative to the 'principalism' of Beauchamp and Childress. Whereas the 'four principles' provide a tool for conceptualising ethical conflicts in the abstract, the so-called 'four-box' or 'four quadrant' approach examines not just the ethical dimensions of the case, but also the medical facts and the legal, regulatory, and organisational context within which decisions are made (Jonson et al. 2006, p. 11).[3]

One of the most influential accounts of clinical ethics consultation, put forward by the American Society for Bioethics and Humanities, draws attention to the central role played by values in healthcare and the potential for value conflict in the delivery and receipt of care (Campbell and McCarthy 2016). According to this account, clinical ethics consultation is a process which aims to "*resolve uncertainty or conflict regarding value-laden concerns that emerge in healthcare*" (ASBH 2011 p. 2). This process is intended to "[help] the relevant decision-makers to fashion a plan that respects the needs and values of those involved and that is within the bounds of ethical and legal standards" (ASBH 2011, p. 7). Information gathered should be accurate and all parties affected by the situation should be represented in the consultation or given an opportunity to voice their perspectives. In the 'real-world' clinical setting, gathering information can be a time-consuming and complex task which requires an appreciation of the nature of interpersonal dynamics and power relationships. Chart reviews and multiple interviews are accompanied by scrutiny of the clinical decision-making process itself: the values and assumptions which underlie it, the responsibilities of the decision-makers, the potential harms and benefits associated with competing courses of action, and the rationale provided for the decision taken (Campbell and McCarthy 2016).

Depending on the nature of the service and its organisational mandate, the outcome of this process ranges from a determination of ethically-permissible options to the provision of a recommendation to those with ultimate responsibility for the decision. Most clinical ethics services see their role as advisory rather than executive: they engage with individual cases by invitation only and their function is to assist healthcare professionals faced with difficult decisions to "*think through and reflect upon the decisions they make*" (Slowther et al. 2002, p. 5), rather than to usurp their authority.

Issues Which Trigger Requests for Clinical Ethics Consultation

Clinical ethics support can be requested in many different kinds of situation, most commonly in cases of conflict between the clinical team and the patient – or member of the patient's family – relating to treatment decisions, or in situations in which members of the clinical team disagree about the nature of the treatment provided to a patient or the manner in which it is provided. Certain kinds of decisions are more

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[3] Please see Appendix 15.1 at the end of this chapter.

likely to trigger requests for ethics consultation: decisions to limit – or prolong – treatment at the end of life, decisions involving patients who lack capacity or have ‘borderline’ capacity, decisions relating to discharge or long-term care, and, increasingly, decisions influenced by limited resources or lack of health insurance. Strained interpersonal dynamics and poor communication are often at the root of these conflicts, but organisational factors such as flawed management practices or lack of transparency can also give rise to requests for support. In a recent national survey, providers of clinical ethics services in the US included in their role description the additional goals of protecting patient rights, increasing patient or family satisfaction, preventing future ethical problems, providing moral support to staff, reducing unwanted or wasteful treatments and reducing the risk of legal liability (Fox et al. 2007, p. 16). Benefits of engagement with clinical ethics services cited by clinicians in the US and UK include greater transparency and accountability in the decision-making process, exposure to alternative perspectives, improved communication, help in weighing outcomes, professional reassurance and opportunity for specialty-specific capacity-building (Orlowski et al. 2006, p. 501; Johnston 2010, p. 205–6)

Barriers

Despite the increasing recognition of the value of clinical ethics support services, the practice of clinical ethics consultation remains controversial. Perhaps the most significant barrier to the widespread acceptance of clinical ethics services in healthcare organisations is a lack of ‘high-quality’ evidence for the efficacy of clinical ethics interventions (Slowther et al. 2012, p. 210). Other barriers include failure to achieve ‘buy-in’ from clinicians, particularly physicians, and a lack of understanding of what it is that clinical ethics services actually *do*. Empirical evidence suggests that many clinicians – particularly physicians –remain sceptical about the expertise of clinical ethics service providers (Johnston 2010, p. 205) and are reluctant to share responsibility for managing the care of patients (Gaudine et al. 2011, p. 772; Orlowski et al. 2006, p. 500). In one survey of 344 American physicians, 42% of respondents felt that the most helpful strategy for dealing with ethically-challenging situations was to discuss them with colleagues rather than request an ethics consultation (DuVal et al. 2004, p. 253), while others believed that requesting ethics support undermined the doctor’s role as the primary decision-maker (Orlowski et al. 2006, p. 500). Another common barrier is an unwillingness by clinicians to accept the authority of the clinical ethics service or the legitimacy of its recommendations. While the last 10 years have witnessed a growing momentum in the development of clinical ethics as a practice within healthcare, these and other challenges – lack of standardisation, accessibility issues, growing concern about the quality and consistency of the service provided in smaller, particularly rural hospitals – suggest that if clinical ethics services are to achieve genuine recognition in a culture “*preoccupied with measurability, understood in terms of quantitative performance measures*”, they must be able to demonstrate the value of clinical ethics consultation to the institution they serve (Geppert and Shelton 2016, p. 538). For this reason, there is a pressing need for quality evaluation of existing services and robust, up-to-date information about their range of activities.

Ultimately, clinical ethics services can fulfil their mandate only in organisations in which they are valued and supported by senior management. Clinical ethics services cannot be built from the ground up; healthcare leaders must ensure that the service is integrated within the organisation and visible to staff and patients (Meijburg and ter Meulen 2001, p. 38i–39i). This would suggest, that, in order to function optimally, clinical ethics support services must be embedded within a larger organisation ethics framework.

Case Study[4] The following case, referred to the clinical ethics committee at a large Dublin hospital, illustrates the nature of clinical ethics consultation discussed above.

Hospital Clinical ethics referral form:

Name:	*Elizabeth Wong*
Date:	*20 May 2016*
Position	*Clinical nurse manager*
Phone/Bleep	*9746*
Email:	*Elizabeth.wong@hse.ie*

Please provide a description of your query in the box below. We will respond to this message within 24 h.

Patient (F 80) had motor accident earlier in week. Fractured jaw & broken elbow. Pt. has dementia. Daughter doesn't want anything done. No surgery to her jaw and was taken off oxygen. Has DNR. Attending put her back on oxygen because she was struggling to breathe. Nurses feel she would be fine with surgery and food (pt. was taken off food because she had been scheduled for surgery) in a nursing home.

In this situation, the clinical ethics committee must first obtain a comprehensive picture of the situation, before taking any action to address the issue.

From her chart, the committee members learnt that Mrs. Corbett, the patient, had been admitted five days previously with minor injuries resulting from a car accident – a fractured wrist, dislocated elbow, broken rib, and a fractured mandible. All of her injuries, bar the mandible fracture, had been repaired, and an operation to fix the jaw fracture had been scheduled for the previous afternoon. The morning before the surgery, she went into respiratory distress and had to be intubated. She was extubated that same evening, but the surgeon postponed the surgery indefinitely and placed a DNAR order in her chart. In the chart, Mrs. Corbett was described by the surgeon as 'a woman with a poor quality of life following injury and arrest'. The following morning, Dr. Boyd, the surgeon, met the patient's daughter and legally-appointed decision-maker to discuss Mrs. Corbett's care. Dr. Boyd noted in the

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[4] This case-study takes as its point of departure a case described by (Finder 2008). The facts of the case have been reproduced, but the outcome has been changed substantially, with the author's permission.

chart that Mrs. Corbett 'requires extensive surgery, placement of a feeding tube, and nursing home care'. The patient's daughter, Breda, was documented as stating that her mother had said that she would not want to be in a nursing home long-term. She also stated categorically that she was not able to look after her mother at home. The social worker noted in the chart that Breda was 'concerned about her mother's declining mental status'. A decision was made not to operate but to keep Mrs. Corbett as comfortable as possible.

Armed with this information from the chart, two committee members met with Elizabeth, the clinical nurse manager who had contacted the committee, two of the nurses looking after Mrs. Corbett, and the social worker responsible for Mrs. Corbett's case. For the nurses, the main issue was the abruptness of the decision to forego the option of surgery. The social worker maintained that Breda, Mrs. Corbett's daughter, was making the wrong decision. All three felt that she didn't seem interested in what was going to happen to her mother. She seemed cold and they had overheard her arranging to meet friends for lunch just after the decision had been made to opt for comfort care for Mrs. Corbett. The committee members were unable to speak to Mrs. Corbett herself, who continued to stare straight ahead without looking at them and could not be engaged in conversation.

Later in the day, the committee chair spoke to Dr. Boyd on the phone. Dr. Boyd said that he found Breda to be a devoted daughter and he made it clear that he believed that resetting Mrs. Corbett's fractured jaw was not in her best interests. Although fixing her jaw would be relatively straightforward, the recovery process would be complicated. Mrs. Corbett would need full-time nursing care for up to six months. Breda would not be able to provide this and her insurance didn't include a home care option, so Mrs. Corbett would have to go to a nursing home against her wishes. She would need to have a PEG tube inserted since her jaw would have to be wired shut and, according to Dr. Boyd, it was likely that she would develop pneumonia and require a tracheostomy, possibly leading to long-term dependence on nursing care. For Dr. Boyd, the choice was between fixing Mrs. Corbett's jaw and condemning her to the nursing home and a slow death, on the one hand, or keeping her comfortable and allowing her to die with dignity, on the other.

Because Mrs. Corbett seemed unable to communicate, a capacity assessment was carried out the following day which found her incapable of making treatment decisions. Breda could not be reached by phone and didn't return to the unit. The nurses watched Mrs. Corbett deteriorating and felt that they had failed her. Some nurses felt strongly that, if they allowed her to die, they would be complicit in her death.

The committee chair convened a meeting and invited all staff members involved in Mrs. Corbett's care to exchange their perspectives on the situation. During the meeting, Dr. Boyd was surprised by the nurses' reaction and admitted that he should have consulted them before making the decision not to reset Mrs. Corbett's jaw. He learnt that the hospital had a new DNAR policy mandating that resuscitation decisions should be made collaboratively rather than unilaterally. In turn, he was able to inform the nurses that Mrs. Corbett's husband had died a year previously after a long illness and that, even though she had no written advance *directive, she had stated repeatedly that she did not want to go to a nursing home or be 'tied up to tubes'. He also told them that Breda was the single mother of a teenage son with autism and that she had been struggling in recent months to cope with his behaviour. A colleague whom Dr. Boyd consulted for a second opinion agreed that recovery from the jaw operation would be complicated for Mrs. Corbett. After the meeting, staff felt that they had a fuller picture of the situation and most of the nurses accepted Dr. Boyd's rationale. They also came to understand that they had judged Breda too hastily, and a family meeting was organised to offer Breda a respite package. Mrs. Corbett was kept comfortable until her death the following week and Breda was able to be present at her death. Afterwards a debriefing session was held to provide nursing staff with an opportunity to explore the difference between 'passive' euthanasia and the justification for withholding of treatment in cases like Mrs Corbett's.*

What this case illustrates is the importance of examining contested decisions and making underlying values explicit, providing a non-threatening forum where differences in perspective can be explored, and facilitating communication between clinical disciplines. Beyond addressing this impasse at the 'micro' level within the clinical setting, the responsibilities of the clinical ethics service include briefing staff in relation to new policy initiatives and building ethics capacity among staff by facilitating discussions of controversial topics such as euthanasia. Discharging these responsibilities effectively requires that the clinical ethics service is proactive, visible within the organisation, and supported by senior management.

The Growth of Organisation Ethics

As indicated above a clinical ethics service is more likely to function optimally within the context of an organisational ethics framework. The concept of organisation ethics was imported into the healthcare domain from the field of business ethics during the last quarter of the twentieth century. Business ethics is concerned with the ethical implications of business practices and commercial activity and it came to prominence as an academic discipline following a number of corporate scandals in the 1970s and 1980s. Although business ethics may be narrowly viewed in terms of compliance – avoidance of activities which violate laws and regulations – it also addresses a range of other issues, including fair competition, employment relations, managerial practice and corporate social responsibility. In resource-rich countries, recent decades have witnessed an inexorable move towards an institutionalised, market-oriented approach to healthcare provision (Shale 2012, p. 13). Radical changes in the delivery, management, structuring and reimbursement of healthcare have resulted in the 'corporatisation' or 'industrialisation' of healthcare provision (Shale 2012, p. 12). These changes have led to greater external scrutiny of the organisational and managerial practices of healthcare organisations, mirroring the increased attention paid to compliance in the corporate and financial sectors (Rorty et al. 2004, p. 76). Organisation ethics programmes in healthcare institutions were put in place partly in response to demands for greater transparency and accountability in healthcare management, and partly to support the effective delivery of care in an increasingly complex social, financial, and regulatory environment.[5]

> Organisation ethics in healthcare represents a shift from thinking about how decisions are made at the level of individual patients and clinicians to identifying ethical tensions in the larger system within which the clinical encounter takes place: the structures which govern how healthcare is administered, rationed, purchased, and paid for (Childs 2000, p. 235). In this context, organisation ethics can be described as an attempt to understand and address the ethical issues associated with the financial and managerial operation of healthcare organisations, including the business, professional, and contractual relationships which underpin the daily running of these institutions (Spencer et al. 2000, p. 212). Otherwise put, organisation ethics addresses the ethical issues faced by those who manage and govern healthcare organisations and analyses the "*[effects] of their decisions and practices on patients, staff and the community*" (Gibson et al. 2008, p. 243).

Publicly-funded healthcare organisations, unlike corporations, whose primary goal is to maximise shareholder profit, have a social mandate to provide healthcare – regarded as a universal or primary 'good' – to a given population (Door Gould 2001, p. 28). Because healthcare provision is rooted in an ethical tradition, many healthcare organisations have mission statements, codes of ethics or terms of reference which emphasise this legacy (Reiser 1994, p. 28). The tension for such organisations is that they must discharge their public responsibilities in an environment dominated by market forces and fiscal constraints. As such, healthcare organisations have a number of competing obligations. They are accountable for the quality of the care they provide to members of the public, but they must also ensure competence and promote professional excellence among their employees and, as financial entities, they must engage in effective stewardship of resources in order to maintain economic viability (Rorty et al. 2004, p. 88). An effective organisation ethics programme must ensure that management practices enable both individual employees and the organisation as a whole to "*do the right thing*" (Pearson et al. 2003, p. 26). Ultimately, the goal of organisation ethics is to enable an organisation "*to conduct itself with integrity in the full range of its activities*" (Pearson et al. 2003, p. 32).

Mission and Values: Avoiding 'Institutional Dissonance'

Values permeate healthcare provision at every level and the nature of healthcare delivery is such that healthcare organisations are required to devise a set of core values which meet 'societal expectations' (Graber and Kilpatrick 2008, p. 179). The values espoused by healthcare organisations are articulated in mission statements – values such as respect, inclusiveness, compassion – are often 'aspirational' and aligned with the professional values which govern clinical practice (Boyle et al. 2001, p. 75). Organisation ethics programmes represent an organisation's efforts to

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[5] In 1995, the Joint Commission: Accreditation, Health Care, Certification (JCAHO) introduced an accreditation standard which required organisations to have a mechanism for addressing organisation ethics issues.

define its mission and devise core values which are appropriate to its mission. They enable the organisation to identify situations in which important values come into conflict and to devise processes for the resolution of these conflicts. Perhaps most crucially, they monitor the relationship between the values espoused by the organisation and its behaviours and practices (Pearson et al. 2003, p. 32). A successful organisation ethics programme should avoid what Reiser terms ‘institutional dissonance’: it should ensure that there is no contradiction between “the behaviours organisations urge and the actions they take” (Reiser 1994, p. 28). Certain fundamental ethical obligations follow from this understanding of organisation ethics: key stakeholders must be involved in identifying the values by which the organisation’s conduct will be guided, the organisation must commit itself to a clear and ‘forceful’ statement of these values and it must make these values known to its entire staff (Pearson et al. 2003, p. 33). In a sense, this means giving staff ‘ownership’ of the organisation’s values. Reiterating core values and incorporating them into organisational activities may over time “allow them to become internalised by the organisation’s directors and employees” (Boyle et al. 2001: 75), and this support at the level of senior management should be visible throughout the organisation (Childs 2000, p. 237). Finally, the organisation must ‘walk the walk’ by ensuring that it acts on the values it has espoused (Pearson et al. 2003, p. 33).

The most direct way for an organisation to ‘enhance and maintain’ its espoused values is for it to ensure that the content of its policies and procedures reflects these goals and values; the principal role of an organisation ethics programmes is to make this coherence explicit (Chen et al. 2007, p. S14). Policies and procedures allow the organisation both to reinforce its mandate and to ‘filter’ external influences. Procedural transparency is vital: the organisation must be open about the process by which priority-setting decisions are made and it must specify steps for individuals to follow if they disagree with organisational decisions (ibid.). In organisations as complex as healthcare institutions, legitimate conflicts of roles and expectations arise; however, the potential for conflict can be reduced if the organisation has a “*strong and positive ethical climate and culture*”, namely, a set of beliefs, practices, and ways of thinking which is shared by individuals within the organisation (Chen et al. 2007, p. S14). The creation of a positive ethical climate requires the organisation to develop processes and structures “*which can address these conflicts while maintaining organisational cohesion*” (Rorty et al. 2004, p. 92). On this view, ethical leadership of an organisation involves an ability to *“[resolve] the tension between competing values and goals when such tension is capable of being resolved, and containing the tension when the conflict is not capable of resolution”* (Shale 2012, p. 15).

Another conceptual tool used to analyse organisation ethics is stakeholder theory. Interactions between clinicians, patients, and family members occur within an organisation which in turn interacts with a variety of stakeholders, and the quality of the care patients receive in part depends on the relationships between these stakeholders (Chen et al. 2007, p. S11). Stakeholders are individuals or groups who benefit from or are harmed by, or whose rights are affected by, the actions of an organisation (Freeman 1999, cited in Spencer et al. 2000, p. 56). A stakeholder can also be defined as an individual or group whose role is central to defining the mandate or purpose of the organisation or whose relationship to the organisation is important for its continued existence or success (Spencer et al. 2000, p. 56). On this view, the interactions between stakeholders constitute the operation of the organisation. A healthcare organisation's most important 'internal' stakeholders are patients, family members, healthcare professionals, managers, and hospital executives, while 'external' stakeholders include suppliers, payers, policymakers, insurers, regulatory agencies, and members of the broader community. Stakeholders in healthcare organisations, although their interests may collide, share a common purpose: the delivery of high quality care at a reasonable cost to the population served by the organisation (Rorty et al. 2004, p. 88). The organisation's obligations, then, follow from this common goal: to provide quality care, to ensure the competence and expertise of its clinical staff, to establish effective management systems, and to maintain economic viability. For some commentators, the applicability of stakeholder theory to an analysis of organisation ethics in healthcare resides in its ability to *"[capture] the importance of a plurality of values and moral agency on different levels*" (Spencer et al. 2000, p. 56). Others, however, argue that its purchase is limited because it cannot adjudicate conflict between different parties "*where each believes that their needs should take priority"* (Shale 2012, p. 227).

Organisation ethics programmes, like clinical ethics initiatives, are heterogenous in the forms they take and the activities they perform will differ from organisation to organisation; what is important is that they are inclusive in orientation and *"recognise the legitimacy of the ethical perspectives of the various stakeholders [within the organisation]"* (Chen et al. 2007, p. S14). An organisation may establish an organisation ethics committee or appoint an individual to run its organisation ethics programme. The appointed body or individual should report to senior executives within the organisation, while remaining sufficiently independent from senior management to ensure that any recommendations made are impartial and unbiased. Healthcare organisations face enormous challenges – not least the problem of negotiating between unlimited need and limited resources (Shale 2012) – and organisation ethics is commonly associated with managing the tension between the need to maximise resources and the need to optimise care (Graber and Kilpatrick 2008, p. 188). Robust justification for decisions relating to bed allocation, staffing levels, discharge planning, and medication purchasing is required and should be clarified in policy documents.

Organisational dimensions of clinical problems include such issues as the absence of policy guidance in situations in which codes of practice are ambiguous, inadequate training of employees leading to lack of competence, poor communication practices and ineffective mechanisms for dispute resolution, inadequate attention to conflicts of interest and under-resourcing of certain forms of care. But other issues such as business development and fund-raising, risk management, workplace relations, and safety and disclosure protocols all fall within the remit of organisation ethics, understood as a mechanism which enables an organisation to balance its own needs with the needs of its patients, its employees, and the community at large (Gibson et al. 2008, p. 246). An organisation confident in its commitment to ethics would create mutually reinforcing roles for its clinical ethics service and its organisation ethics programme.

The Intersection Between Clinical and Organisational Ethics

Ultimately, clinical and organisation ethics activities exist along a continuum; no clear distinction can be drawn between them (Spencer et al. 2000, p. 31). Decisions made at one level in an organisation may have *"unanticipated consequences which threaten values or priorities at some other level"* (Rorty et al. 2004, p. 91). Many, if not all, of the cases which come to the attention of clinical ethics services have an organisational dimension because clinical decisions *"affect, not only the patient, family, and care team, but multiple other interests throughout the organisation and in other parts of the health system"* (Chen et al. 2007, p. S11). Organisational culture and practices 'shape' the kinds of situations which are encountered by clinical ethics services (Shale 2012, p. 224). Because of this interdependence, a well-integrated clinical ethics service may serve as a 'barometer or early warning system' which can expose larger conflicts or structural problems within the organisation (Collier et al. 2006, p. 332). For example, an increase in consultation requests or an emerging pattern of referrals from a particular unit may signal a need for organisational changes to be made to prevent recurrence of a given issue (Spencer et al. 2000, p. 31), and as such *"may require an institutional rather than an individual response"* (Collier et al. 2006, p. 332). Conceptualising the role of ethics in institutions therefore "*requires more than [simply] dispute resolution in individual cases"* (Collier et al. 2006, p. 333).

Gibson et al. (2008) provide a distinction between three categories of ethical issues in healthcare, which emphasises the extent to which the domains of clinical and organisational ethics are interwoven. First, ethical issues may arise in clinical care as a result of decisions taken elsewhere in the organisation; second, ethical issues may arise in the clinical setting which have larger implications for the organisation as a whole, and finally, ethical issues may arise which are related specifically to the business and managerial aspects of the organisation (Gibson et al. 2008, p. 243). Given this interrelationship between clinical and organisational ethics, ethics should be seen *"not as a compartmentalised discipline, but an institutional attitude (…) reflected as fully in the relationships between employees and the administration as in the hospital's DNR policies [and] (…) integrated into decision-making at all levels of administrative responsibility"* (Wolpe 2000, p. 194).

Implications for Healthcare Practice

The emergence of clinical ethics and organisation ethics necessitates a reconceptualisation of the 'traditional' concept of clinical governance to incorporate an explicit recognition by healthcare leaders of the ethical dimension of healthcare provision. In part, this recognition is a response to the obligations imposed on healthcare professionals by increasingly demanding codes of professional conduct. In part, it is a response to a changing culture within healthcare which compels – at least on the surface – respect for individual values as a pillar of patient-centred practice. In spite of the challenges mentioned above, the growth of clinical ethics support services within a relatively short time period signals an increasing appreciation by healthcare leaders of the role of values in healthcare and the importance of due process in healthcare decision-making. Within healthcare organisations, the establishment of clinical and organisational ethics initiatives draws attention to the moral mandate of the organisation and reinforces the values that "define the healthcare institution as a moral community" (Gillon 1997, p. 204). Both kinds of initiative can be seen as promoting fair, inclusive, and transparent processes for the resolution of ethical issues. Both mechanisms contribute to greater intra- and inter-professional understanding by providing additional opportunities for communication and deliberation and fora for the exploration of diverging perspectives. Both provide opportunities for role and value clarification and allow employees a greater insight into the operation of their organisation.

Conclusion

Clinical practice is ethically 'loaded' and it is a fallacy that clinical decisions can be isolated from their ethical implications. It cannot simply be assumed by healthcare managers *"that the values associated with ethical healthcare delivery are already embedded within clinical and organisational decision-making*": these values need to be made explicit and promoted (Chen et al. 2007, p. S16). While there is as yet a dearth of evidence to support the value of clinical and organisation ethics programmes to healthcare organisations, it is not an unreasonable assumption that all categories of health and social care staff will potentially benefit from an organisation's genuine commitment to the establishment of mechanisms to promote awareness of ethics, develop an ethical culture, and build ethics capacity. Time and tenacity are required for these initiatives to bear fruit; if an organisation's culture can be likened to a 'moral space', this space is a continuous work of progress and providers of clinical and organisational ethics services are its *"architects (...) as well as meditators of the conversations which take place within that space"* (Walker 1993, p. 33).

Key Learning Points

- Advances in medical technology, greater diversity in the patient population, legislative developments and recent changes in the organisation, delivery, management, and financing of healthcare have resulted in an enormously complex healthcare system which is fraught with ethical challenges.
- Clinical and organisation ethics are responses to the need for new approaches to the management of these challenges.
- Clinical ethics identifies and addresses ethical challenges arising in the clinical setting.
- As a form of practice, clinical ethics has matured more rapidly in Canada and the US than in Europe.
- Organisation ethics addresses ethical issues relating to the management and financial operation of healthcare institutions.

Appendix 15.1

Jonsen Sieler and winslade's 'Fur-Box' method for analysing ethically- challenging situations (2006).

Medical indications (beneficence and non-maleficence)	Patient preferences (autonomy)
What is the patient's medical problem? History? Diagnosis? Prognosis? Is the problem acute? Chronic? Critical? Emergent? Reversible? What are the goals of treatment? What are the probabilities of success? What are the plans in case of therapeutic failure? In sum, how can this patient benefit from medical/nursing/psychiatric care, and how can harms be avoided?	Is the patient mentally capable and legally competent? Is there evidence of incapacity? If competent, what treatment preferences is the patient stating? Has the patient been informed of benefits, risks, understood this information, and given consent? If incapacitated, who is the appropriate surrogate? Is the surrogate using appropriate standards for decision-making? Has the patient expressed prior preferences (e.g., an advance directive?) Is the patient unwilling or unable to cooperate with medical treatment? If so, why? In sum, is the patient's ethical and legal right to autonomous choice being respected to the fullest possible extent?
Quality of life (principle of beneficence, non-maleficence, respect for autonomy)	Contextual features (principles of loyalty and fairness)
What are the prospects, with or without treatment, for a return to a normal life? What physical, mental and social deficits are likely to result if treatment succeeds? Are there biases which might prejudice the provider's evaluation of the patient's quality of life? Is the patient's present or future condition such that his continued life could be considered undesirable? Is there any plan or rationale to forego treatment? Are there any plans for palliative or comfort care?	Are there family issues which might influence the patient's treatment decisions? Are there provider issues – physicians and nurses – which might influence treatment decisions? Are there financial and economic factors involved? Are there religious or cultural factors involved? Are there limits on confidentiality? Are there problems of resource allocation? How does the law influence treatment decisions? Is clinical research or teaching involved? Is there any conflict of interest on the part of providers or the institution?

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