

Preface

INTRODUCTION

Women's health is composed of a broad range of both normal physiological events in a woman's life, and conditions which occur as a result of abnormality of the genital tract and pregnancy. During the last century, the field of women's health (and ill health) have rapidly changed and evolved as a clinical discipline. This is in part due to the changing roles and expectations of women. The feminist movement and newspaper articles with headlines that read "the unfortunate experiment," resulted in the medical profession realizing that high standards and an informed approach were needed.

We are now at a point where the care of women through all parts of their life, whether it is puberty, pregnancy, or menopause, is generally of a high standard throughout the developed world. Care involves screening and prevention of disease, fertility control, pregnancy care, neonatal care, and management of gynecological disease.

Within women's health expectations of good quality care are high. Health professionals working in the area have been amongst those who have responded to the challenge to provide women and their babies with evidence-based care. For example, the Cochrane collaboration is a worldwide network of interested researchers who assess quality of research and collate the best to produce meta-analyses to guide practice. The groups now cover many disciplines within medicine, but the first group's set-up (and still the majority) is from women's health.

With so much information, both about individual women and vast amounts of research, managing this data is essential. Computing power has revolutionized life in the modern world. Within health, information, communication, data storage, and decision making have all been changed immensely by computing. We are now at a point where we cannot imagine running our lives without it.

The field of health informatics has been rapidly evolving over the last 20 years. There has been an explosion of interest in all medical fields and women's health is no different. Who are the health informaticists in women's health? As is usual in a new and evolving field, initially the "experts" are self-taught with an interest, and come from a range of backgrounds such as doctors, nurses, midwives, computer scientists, librarians, information scientists, and engineers. More recently however, many teaching institutions have developed courses in health informatics and post graduate study in the area is often easily arranged via e-learning.

In tandem, a number of areas were initially developed in women's health informatics. In the 1980s a number of early informaticists started to collect maternity data on databases. In Chapter V, Parry describes the development of the early electronic health records which stored information gathered on a database. The development of the World Wide Web led to electronic communication. This allowed communication between health professionals for advice and support. It also allowed new information to be more quickly disseminated and incorporated into practice. In the 1990s many research journals

started to put an electronic version of the publication on the Internet, allowing more rapid and wider access to research.

Doctors have always jealously guarded their ability to make a diagnosis and institute the correct management. Even in this area computing power has had an increasingly significant role from the early days of clinical alerts to complex assessment of the antenatal CTG, which can now outperform a human (see Chapter X).

This book describes a number of areas within women's health informatics. Clearly where technology is involved, there are commercial applications within the area. In some cases, certain applications will be referred to. These are to allow examples to be given and do not necessarily indicate an endorsement of the product by the author. As an informatics book, many references are to Internet-based sources. Apologies if these have changed following publication, however judicious use of the Internet archive, www.waybackmachine.org, may allow the resurrection of even outmoded or updated references, for the determined or those requiring academic completeness

THE CHAPTERS

The first two chapters provide some background information. In the first chapter, Stone introduces the novice reader to clinical Women's Health. For a reader coming from a non-clinical background, this chapter will provide a brief overview of the clinical area of women's health. Clearly, the reader who already has prior knowledge in this area may find that it is not necessary to read this chapter. Chapter II examines the issues around the ethics and medicolegal safety in women's health informatics. Fade uses examples to illustrate potential issues and clearly legalities, in particular, institutions will depend on the overarching national legal framework, though the ethics of women's health informatics are generally applicable. If one is planning to use data collected on women, it is imperative that he or she has a clear understanding of local regulations regarding the individuals' data.

The next section looks at technologies within women's health. In Chapter III David Parry addresses coding and messaging systems – essential for the large-scale use and sharing of information. In Chapter IV Gareth Parry examines the wealth of health informatics as it pertains to the primary healthcare setting. The primary care physician provides “cradle to grave” care and is the key individual who coordinates a woman's care. In an ideal situation he or she will have access to all the woman's health data wherever it is recorded. Chapter V examines the concept of the electronic health record and the holy grail of a parallel “cradle to grave” electronic health record which can be easily accessed by all the relevant caregivers involved in one woman's care. One of the many areas where there has been a real explosion of data storage is imaging technologies. In Chapter VI, Graham Parry describes how images from radiological tests: primarily ultrasound, are used. He looks at storage, image manipulation, also covering validity and teaching.

The next section focuses on pregnancy. Pregnancy is a discrete event with a defined end-point. This makes it ideal for the application of statistical measures. Chapter VII looks at the range of maternity information that can be gathered, and then examines the definitions which can be applied. Uses for this information are also included. In Chapter VIII, a team representing the Canadian Perinatal Network Collaboration, look at the development of perinatal databases and the more complicated challenge of networking between units. They use their own leading system in British Columbia as an example. Maternal outcomes are uniquely linked to fetal/neonatal outcomes. Neonatal databases provide the complete dataset to a pregnancy. In Chapter IX, Battin and the colleagues describe neonatal database development. The authors are practicing neonatologists in one of the biggest units in Australia and developed their

own in-house database. In Chapter X, Westgate describes the role of computing to aid decision making in interpretation of the fetal cardiotocogram (CTG). This provides an eloquent example of how artificial intelligence can be better than human intelligence. For more background on this refer to Chapter XV.

Gynaecology is the area of medicine concerned with the female reproductive organs and includes areas as diverse as infertility, delayed puberty, menorrhagia, incontinence, and oncology. Cervical cytology (Pap smear) has been an important medical intervention and has resulted in a reduction in the incidence of cervical cancer by detecting the pre-malignant state which is easily eradicated before progression to invasive cervical cancer. However, as any test, cervical cytology readings can be inaccurate where there is significant human involvement. In Chapter XI, Pantanowitz and the co-authors from Baystate, USA, explore the role of computing to try to reduce error within this important public health area. In Chapter XII, Elit and the co-authors from Canada, describe the information gathering and storage in women undergoing surgery for ovarian cancer. This is a region-wide system and incorporates elements of Internet use for data sharing and extensive efforts to use a seamless electronic health record (see Chapter V). Although a specific area of women's health is the focus of this chapter, it provides an excellent generic framework for the development of a regional/countrywide gynecological electronic data storage and data sharing system.

For the reader who is a clinician, how many times has a patient sat down in your rooms and brought out a pile of information downloaded from the Internet? This is now a reality and knowledge is available for all, though the interpretation is often lacking. In the last section of the book, this information "overload" and its reasonable management is explored. In Chapter XIII, Abuidhail provides a broad review of the use of electronic information sources for education and support of women and their caregivers. This includes telenursing and telehealth. In Chapter XIV, Kirtley (a librarian and information scientist) provides an extensive review of the available electronic information sources in women's health for health professionals working in the field. In the final chapter, David Parry looks at decision analysis, a system of helping individuals to make decisions using computer support to make sense of the known possible outcomes of an intervention.

THE FUTURE

Who would have thought that 20 years ago a device the size of your hand could allow one to talk to a friend across the other side of the world, check the latest world news, and write, perform analysis, and submit a paper electronically! We are talking about the latest PDAs of course. The amazing explosion of computer technology over the last 20 years has been incredible. Now with the technology becoming smaller and cheaper, further amazing changes are occurring.

In the area of women's health informatics systems for data storage, image storage, data interpretation, and analysis are quickly becoming mainstream and commercial rather than home-grown. What is really lacking is a cohesive approach and universal language to allow large networks to function well. Only in the area of imaging with the DICOM system has this part way been achieved. In the future, clinicians will collaborate more, as diseases become rarer and individuals experience less. They will push for systems which can also collaborate between centers to allow data sharing. Whether this will happen we will have to wait to see.

Smaller devices mean that data is likely to be collected in a more ubiquitous way in the future with hopefully better and more extensive data capture. This coupled with cheaper devices will also hopefully translate into more use in the resource constrained setting where the majority of maternal deaths occur.

CONCLUSION

Women's health informatics is now "coming of age". It is an established area of health informatics and comprises a broad range of themes. There is currently no other book in this area and the aim of this publication is to provide interested readers with an insight into women's health informatics. We are not providing a comprehensive textbook as the margins of the field are somewhat "fuzzy" and there is no clinical role for an expert in the whole breadth of the field. Rather, this book provides an introduction for a new enthusiast, whatever field they come from, and in-depth chapters from leading authors in their respective fields. Researchers, clinical, and technical workers in this area should find this book a starting point for future work as well as an accessible introduction to those areas that they may feel uncertain in or unqualified. It is hoped that future editions will cover exciting and more importantly, clinically beneficial developments in this area. Change is constant in both women's health research and IT, and it is certain that the future developments imagined above will not be complete. The readers of this book may be those who will make the vision a reality.

Emma Parry
The University of Auckland, New Zealand

David Parry
Auckland University of Technology, New Zealand