



A PERSONAL PRENATAL HEALTH RECORD AND SOFTWARE PROGRAM FOR CULTURALLY DIVERSE URBAN AND RURAL COMMUNITIES¹

Introduction

I am excited to introduce Maternl[®]. Maternl[®] is a unique, new software program developed specifically to address disparities in maternal and child health. The CenterPoint of the program is a web-based, cross platform Personal Prenatal Health Record (PPHR). The PPHR is a portable, secure and interactive electronic personal health record, designed specifically for pregnant women in underserved, urban and rural communities, nationally and internationally. Many women in underserved communities do not have readily accessible and continuous access to pre-natal care, may get fragmented care at multiple facilities ("unregistered" patients) and may present to a provider in one or more of those facilities who is unfamiliar with her health history, family history and her prior physical examinations and findings, knowledge of which would contribute to a higher quality and safer prenatal visit / encounter. As a portable, mobile, secure and interactive personal health record, Maternl[®], is a contemporary substitute for the commonly used handwritten "paper card" format to record pre-natal care information. Such a card carried by the patient, sometimes referred to as a "*Pregnancy Passport*," is sub-optimal in today's contemporary healthcare and health information technology environment. A readily available Internet-based program / mobile smart phone / tablet application to collect, store and access personal prenatal healthcare information, designed specifically for the target population, improves the quality of the point-of-service encounter for transient and "unregistered" patients arriving for pregnancy related care. As perinatal morbidity, mortality and prematurity rates are higher in urban and rural, underserved, minority communities, Maternl[®] utilizes the many advantages of health information technologies to improve storage, access and retrieval to this important information, disseminate pregnancy-related resources and referrals based on decision support algorithms and the users' current needs, provide a searchable database of centers where a patient without a healthcare provider can *GetCare*, and a rich collection of poems and writings to support and comfort those who have experienced a pregnancy or newborn loss.

Many women in underserved communities do not have readily accessible and continuous access to pre-natal care, may get fragmented care at multiple facilities ("unregistered" patients) and may lack a primary pre-natal healthcare provider who is familiar with the patient, her health history and family history, her prior physical examinations and her laboratory/Ultrasound findings. Providers of care to pregnant women in these settings often see patients, if patient can find the point of care service, in an emergency setting such as the labor floor or emergency room without access to prenatal visit information such as their pregnancy / medical history, prior examinations and laboratory and imaging findings. These render the emergency visit suboptimal and oftentimes unsafe. Thus, there is a need for a reliable and immediately available prenatal health record in order to provide improved quality of the prenatal visit.



Background

I am an Obstetrician and have devoted my entire professional career to provide optimal prenatal and obstetrical care. I have attended thousands of births and directed the labor floor of a large, safety net hospital in New York City. Throughout, I have always had a striving to bring safe delivery, comfort and healing to children, born and yet to born, and to mothers through their years of childbearing and beyond. It has been the cause in my life. I have been uplifted by the triumphs of birth and healing and depressed by the failures. Yet I have always tried to look beyond the failures in search of the triumphs. (see Full Bio and CV). As the founder and developer of Maternl®, I have been able to uniquely design this program based upon this experience and my experience creating and managing the Hygeia Foundation for Perinatal Loss and Bereavement, Inc (aka:Hygeia Foundation, Inc.) (1995-2012).ⁱ The Hygeia Foundation, Inc. was a non Profit, 501-c-3 organization whose mission was to comfort those who grieve the loss of a pregnancy or newborn child (from all causes; e.g. Miscarriage, Stillbirth, Neonatal Death, Genetic Disorders, SIDS...), to address disparities in access to healthcare services for medically and economically underserved families with respect, dignity and advocacy and to provide education and resources for maternal and child health to at-risk families. The Hygeia Foundation, Inc. endeavored to improve the awareness of the impact of perinatal, neonatal and infant loss on families, community and society and supports the premise that perinatal and infant morbidity and mortality can be affected by providing *all* women and their families who have experienced pregnancy and infant losses the availability of bereavement counseling, pre- and inter-conception counseling (including an evaluation and understanding of their losses) and access to comprehensive women's healthcare services. Furthermore, it was the commitment of the Hygeia Foundation, Inc. to educate and support healthcare professionals as they care for their patients experiencing perinatal and neonatal loss.

The Hygeia Foundation, Inc. provided comfort to families of all socio-economic and ethnic backgrounds who had experienced the tragedies of pregnancy loss and neonatal death and had an international membership of more than 29,000 families who experienced the tragedy of perinatal and early childhood deaths and the hope for a family subsequent to these losses. The Hygeia Foundation endeavored to improve disparities in access to women's healthcare and pre-natal healthcare services by enabling all women in need of women's and maternal and child health services to find and be introduced to these services with *respect, dignity and advocacy*.

I have reintroduced with Maternl®, many of the strengths and successes of the programs of the Hygeia Foundation Inc. Today, Maternl® provides important tools to monitor each of the mother's pregnancies' progress, help her to better understand their providers' care, and provide a place for comfort and support should a mother incur a miscarriage or very complicated pregnancy that might end with a pregnancy loss, stillbirth or neonatal death. Maternl® is a resource to improve access to pre-natal and bereavement care services for all families who have experienced perinatal and neonatal deaths alienated, particularly disenfranchised women and teens in need of health care access.

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A summary of the goals of Maternl© include:

1. To provide a tool to record, collect, and retrieve all pregnancy prenatal related information
2. To provide comfort and support if a mother / family experience a pregnancy loss or neonatal death.
3. To improve and promote the health of women and children
4. To direct vulnerable and alienated patients into the healthcare system.
5. To reduce perinatal/neonatal/infant mortality
6. To influence healthcare systems, world-wide, to further embrace the poor and vulnerable families in need of health care
7. To offer physician-led access to for vulnerable and alienated women to healthcare services with *respect, dignity and advocacy* for those who have no healthcare provider.

Maternl© and shared decision making

Maternl© provides a tool to help record, store and retrieve pregnancy information and promote shared decision making. Families achieve optimally healthy maternal and newborn outcomes when their care and resources are provided in an atmosphere of open (transparent), effective healthcare-provider communications, a shared decision-making process between and among families, clinicians and nurses (teamwork), evidenced / experiential based practices -all occurring within a milieu of consistent and compassionate care. The patient-provider partnership centers on the doctrine of this shared decision making (SDM), a belief that patients have a fundamental right to understand their medical condition to the best of their abilities and to participate fully with their providers in their care.

The essential elements of SDM include:ⁱⁱ

- a process to improve the knowledge of the risks and benefits of maternity care options and to increase consumer and provider engagement
- a process of information exchange and involvement of patients in decision making
- tools and catalyst that promotes appropriate and entitled high-quality health care by providing thorough, evidence-based information and understanding about the patient's condition
- encouragement for a dialog and personal communication between the patient and the provider in a milieu of trust
- adherence to the "Doctrine of Informed Consent"
- access to sufficient, evidence-based information to make a decision that reflects self-determination, autonomy and control
- to recognize that every pregnant woman has the right to base her maternity care decisions on accurate, up-to-date, comprehensible information

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Summary

Maternl© is a new, pregnancy-specific electronic portal which has been designed specifically for pregnant women to address:

1. Higher rates of perinatal morbidity, mortality and prematurity in urban, underserved, minority communities
2. Coincident disparities in access to prenatal healthcare services and access to and use of available health information technologies. (This division becomes particularly concerning as health information technologies play a greater role in the personal health of the patient / consumer in the general population.)
3. An outdated currently utilized "paper chart format" for maintaining prenatal care information ("Pregnancy Passport")
4. A compelling need to improve compliance with accepted prenatal care standards and procedures and patient education needs via the use of innovative, multiple platforms and approaches
5. Access to comfort, support and bereavement services for those who have experienced a pregnancy loss and/or neonatal death.

Among the many contemporary tenets incorporated in a "Digital Health" milieu, two are overarching: a persistence of what has been called the "digital divide" and an available, accessible and widely accepted "patient-centered record" that goes "everywhere the patient goes."ⁱⁱⁱ Detmer et. al.^{iv} have proposed a concise yet elegant characterization of what is the "digital divide." They define the digital divide as the disparity between those with and those without "the ability to effectively use digital information technology."

It is the mission of Maternl© to address these issues to improve the health of all pregnant women.

ⁱ The Hygeia Foundation is now *Hope After Loss* <http://hopeafterloss.org>.

ⁱⁱ Adopted from: Goldberg, Holly, *The Journal of Perinatal Education*, Volume 18, Number 1, 2009, pp.2-40(9), Springer Publishing Company.

ⁱⁱⁱ Dan Bowman. Fierce Health IT. Health IT momentum must be maintained through 'pivot,': [homepage on the Internet]. [cited 5/1/2014]. Available from: <http://www.fiercehealthit.com/story/health-it-momentum-must-be-maintained-throughpivot-desalvo-says/2014-01-24#ixzz30UipEKJi>

^{iv} Detmer D, Bloomrosen M, Raymond B, Tang P. Integrated personal health records: transformative tools for consumer-centric care. *BMC Med Inform Decis Mak* 2008 Oct 6;8:45