UNIVERSITY OF NEW ENGLAND

AN EXPLORATION OF THE EXPERIENCES OF ADULTS THAT WERE RAISED WITHOUT ROUTINE CHILDHOOD VACCINATIONS

A Dissertation submitted by

Najwa Reynolds

BHSc (University of New England)
BHSc Honours (first class) (University of New England)

For the award of

Doctor of Philosophy

2013

Certification of dissertation

I certify that the ideas, experimental work, results, analyses, software and conclusions reported in this dissertation are entirely my own effort, except where otherwise acknowledged. I also certify that the work is original and has not been previously submitted for any other award, except where otherwise acknowledged.

02/09/2013

Signature of Candidate Date

Abstract

This thesis explores the experiences of adults raised without routine childhood vaccinations. This is a highly contentious topic and despite the substantial number of children that are raised in this way, there is a paucity of literature exploring this group of people and the outcomes of such health care decisions.

This study's theoretical framework is constructed from a phenomenological perspective. A phenomenological methodology guiding this study allowed the researcher to hear the participants' voices as they had experienced this phenomenon. Using a mixed method of data collection enabled the researcher to gain a breadth and depth of the phenomenon in question.

Sixty-seven participants completed the open-ended online survey questionnaire and thirteen participants participated in the in-depth interviews. The data was collected from the survey questionnaire, which then informed the in-depth interviews that followed.

Participants were found to have a high regard for their health and displayed proactive health conscious behaviours. A high level of contentment was found amongst participants in regards to the vaccine decision that was made on their behalf, with a great majority of participants found to have made the same non-vaccination decision for their own children.

This thesis revealed the existence of a significant gap between the lived experience of individual's and the vaccine imperative placed upon the populace. Contributing to the literature, this study gleaned intergenerational insights, directly related to asking participants about vaccine decision-making regarding their own children. In addition, the project elucidated the way in which participants navigated between heterodox and orthodox medicine, in an attempt to meet their health care needs and preferences.

The major conclusions from this study demonstrate that growing up without routine childhood vaccinations can be a positive experience for children, which seemed to go along with a healthy lifestyle and a reverence for the body, as part of a holistic ethos, and a deep sense of personal responsibility for one's own health.

The project conveyed a pronounced need for understanding and tolerance towards individuals that do not vaccinate, or who are not vaccinated due to variant beliefs and ideologies. Respect and tolerance for other viewpoints would be beneficial in building trust and establishing a rapport that is based upon a more communicative, collaborative relationship between health care practitioners and the unvaccinated.

Acknowledgements

This thesis was produced as a result of the support of numerous people to whom I am most grateful:

Special thanks are owed to all of the research participants, who generously gave up their time to participate in this project.

My sincere appreciation is extended to my supervisors, Adjunct Professor Jeanne Madison and Dr Gudrun Dieberg, for their guidance, and for their faith in me and my project.

To my mother, Odette Reynolds, for her unfailing love and support, and for understanding and encouraging my aspiration for scholarship.

To my husband David, for his constant love and devotion.

To my children, Bo and Jai, for their love, and gracious acceptance of a mum who was immersed in all things PhD.

List of Contents

List of Figures and Tables

Figures

Tables

List of Acronyms

ACT: Australian Capital Territory/Canberra

CAM: Complementary and alternative medicine

EBM: Evidence-based medicine

GP: General practitioner

MCI: Mass childhood immunisation

MD: Medical doctor

MMR: Measles, mumps and rubella

NSW: New South Wales

NT: Northern Territory

P: Participant

QLD: Queensland

SA: South Australia

List of Definitions of Terms Used in this Thesis

Orthodox medicine

'The dominant medical system, often referred to as biomedicine. Conforming with established or accepted standards as in religion, behaviour or attitudes' (*Collins Australian Dictionary*, 2009). Orthodox medicine refers to the knowledge, practices, organisation and social roles of medicine in westernised cultures (Good, Hunter, Katz, and Katz, 1979). Disease is viewed as a physical or mechanical disorder with little relationship to an individuals psychological, social and spiritual state (Osemene, Elujoba and llori, 2011).

Heterodox medicine

'At variance with established, orthodox or accepted doctrines or beliefs; holding unorthodox opinions' (*Collins Australian Dictionary*, 2009). Otherwise known as alternative medicine or complementary medicine, the definition of heterodox in the Cochrane Collaboration is 'A broad domain of healing resources that encompasses all health systems, modalities, and practices and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health systems of a particular society or culture in a given historical period' (Fisher, 2005, p. 474). The term heterodox medicine is used throughout the thesis to describe the commonly used complementary and alternative medicine. Complementary medicine suggests that it is used alongside orthodox medicine and denotes a hierarchal differential. Although heterodox medicine can be used alongside of orthodox medicine (Clark-Grill, 2010) it has its own history, philosophy, and ontology and should be acknowledged as such. Authors have warned of isolating heterodox techniques so as to fit them into an orthodox model (Frank and Stollberg, 2004). The term alternative medicine implies that holistic medicine is outside of what is acceptable.

Clark-Grill (2010, p. 79) describes the therapeutic approach of heterodox medicine as building:

> on a holistic ontology of health and illness, in which non-material aspects like spirit, emotion, mind, or balance and equilibrium, inner resourcefulness of the organism, connection, meaningfulness, hope (or their lack of), etc are rated as inseparable from the physical state of health. What we believe health and illness to be, or the ontology of illness, determines what kind of healing approach we use. Ontology of illness shapes the scope of the diagnostic gaze and defines what therapeutic responses are suitable. It also influences which methods can be used in the search for more knowledge.

Integrative medicine

The term integrative medicine refers to the inclusion of complementary and alternative medicine (CAM) modalities in an orthodox medical setting (Barry 2006; Singer and Fisher 2007; Coulter and Willis 2004, 2007). The integration of orthodox and heterodox medicine is divided by epistemological boundaries and is argued to raise conflicts and create confusion due to the way in which the two types of medicine conceptualise and treat health and illness. Several scholars have written further regarding this contentious area (Shuval, Gross, Ashkenazi and Schachter, 2012; Hollenberg and Muzzin, 2010; Baer and Coulter, 2008; Frank, 2002).

Anthroposophy

Anthroposophy is a spiritual movement that was founded at the beginning of the twentieth century by Rudolf Steiner (1861–1925). Steiner, an Austrian philosopher, co-founded anthroposophic medicine with the physician Ita Wegman, MD (1876–1943). Anthroposophy is based on an appreciation of a holistic, natural view of health and life choices. Anthroposophical medicine advocates freedom of choice in health care and natural remedies. Anthroposophical beliefs have been associated with the rejection of vaccination campaigns (Timmermans, Henneman, Hirasing and van der Wal, 2008). This type of medical practice is in favour of letting the body experience certain infections and uses antibiotics, antipyretics and vaccinations restrictively (Alm, Swartz, Lilja, Scheynius and Pershagen, 1999). Many adherents oppose the measles vaccine, with the belief that children gain physical and mental robustness from natural measles infection, when supported by appropriate nursing care.

> In anthroposophic care, health is viewed as a matter of body, soul, and spirit, and a balance between these three. There are anthroposophical medical practices in 80 countries around the world and anthroposophy has been applied in various social domains such as education (Steiner schools), art, architecture, and agriculture (biodynamic farming).
>
> Various countries have reported lower participation of anthroposophical parents in the NIP [National Immunization Program], including Germany, Sweden, Switzerland, Austria, UK, and the Netherlands. (Harmsen, Ruiter, Paulussen, Mollema, Kok, and de Melker, 2012, p. 1-2).

Siedler, Hellenbrand and Rasch (2002) explain that anthroposophical beliefs describe natural infections as an important part of childhood development, claiming that natural immunity provides better immunity than vaccinations, and also that vaccinations can be harmful; therefore this holistic lifestyle encompasses the avoidance of vaccines, antibiotics and antipyretics.

Herd Immunity

The herd immunity theory proposes that for contagious diseases that are transmitted from individual to individual (i.e., influenza) and/or for which humans are an important reservoir (i.e., diphtheria), the chain of infection is likely to be disrupted when large numbers of a population are immunized. This has the effect of increasing the level of population (or herd) immunity and reducing the likelihood that susceptible individuals (i.e., not or incompletely vaccinated, or those in whom vaccination is contraindicated, or considered as less or not-effective) will be infected (Lang, Samaras, Samaras, Govind, and Aspinall, 2011, p. 3).

Measles, mumps, rubella, pertussis, chickenpox, and polio are named as the classic examples of childhood infections (Fine, Eames and Heymann, 2011).

Free-rider

A free-rider is a frequent term in the mainstream literature and is used to describe parents that decline vaccinations and take advantage of the fact that most other children will be vaccinated and offer disease protection for their children. The free-rider is therefore said to avoid the risk associated with childhood vaccines while gaining the 'herd' benefit from the community (Benin, Wisler-Scher, Colson, Shapiro and Holmboe, 2006; Isaacs, Kilham and Marshall, 2004).