AUTOLOGOUS BLOOD DONATION: DECISION MAKING FACTORS USED BY PREOPERATIVE PATIENTS

BY

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A Thesis submitted to the Faculty of Graduate Studies in Partial Fulfillment of the Requirements for the Degree of

MASTER OF NURSING

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Betty A. Frost

A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University of Manitoba in partial fulfillment of the requirements of the degree

of

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TABLE OF CONTENTS

ABSTRACT	4
ACKNOWLEDGEMENTS	6
CHAPTER ONE: Background. Problem and Purpose	8
Introduction	8
Background	9
Statement of the Problem	18
Purpose of the Study	
Research Questions	
Conceptual Framework	20
Definitions	
Summary	
CHAPTER TWO: Review of the Literature	25
Introduction	25
Agency Reviews	26
Patient Perspectives	27
Quantitative Studies	
Synthesis of Findings in the Literature	
Summary	37
CHAPTER THREE: Research Methods	38
Introduction	38
Research Approach	38
Sample Selection	40
Sample Acquisition	
The Interview Setting	
Data Collection	
Data Analysis	
Methodological Rigor	
Ethical Considerations	47
Summary	
CHAPTER FOUR: The Findings	52
Introduction	52
Sample Attributes	52
Qualitative Findings	58
Categories and Themes	59
Preparing for surgery: The likelihood of requiring transfusion	

Autole	ogous Blood Donation: Dealing With The Anticipated Loss of Blood	62
Autole	ogous Blood Donation: The Intervention	70
Autolo	ogous Blood Donation Outcomes: Future Considerations	79
Summ	nary	84
CHAPTER F	IVE: Discussion of the Findings	86
Introd	uction	86
	onship of the Findings to the Sample	
Relati	onship of the Findings to the Research Questions	90
Relati	onship of the Findings to the Conceptual Framework	115
	nmendations	122
	stions for Further Research	123
	usion	
REFERENCI	ES	126
APPENDIX	A	130
	В	
	C	133
	D	

ABSTRACT

Patients undergoing certain types of elective surgery are frequently faced with a reasonable likelihood of blood loss requiring transfusion. Concerns with the transmission of strains of hepatitis and HIV viruses following the tainted blood scandal of the 1980s, has led to the development of new and alternative options to reduce the risk of homologous transfusion. A review of the literature demonstrated that autologous blood donation (donation of blood by an individual for the purpose of transfusion back to the same individual) is a safe and effective method to reduce the risk of homologous transfusion and therefore reduce the risk of blood borne infections. There was, however, a lack of nursing research into the patient's perceptions and experience with autologous blood donation. The purpose of this descriptive study was to gain insight into factors used by preoperative patients to make a decision to donate autologous blood. Becker's Health Belief Model (1974) provided the conceptual framework for developing the semistructured interview guide used to gather data about the perspectives and experiences with autologous blood donation. Twelve patients who donated autologous blood preoperatively participated in the study. Qualitative analysis revealed four major categories that described the patient perspective and experience: preparing for surgery: the likelihood of requiring a transfusion; dealing with the anticipated blood loss during surgery; the autologous blood donation experience; and the autologous blood donation outcomes and future considerations. Demographic findings were consistent with the literature that a major benefit of autologous blood donation is the reduced risk for homologous blood transfusion. Other factors such as choosing autologous blood donation from multiple options presented, amount of anticipated blood loss during surgery and

cost-effectiveness of autologous blood donation were not revealed as motivators used in decision-making. The physician played a key role in recommending autologous blood donation. The nurse played a key role as a resource prior to and during the autologous blood donation. Implications for care providers regarding providing patients with information they both want and need in order to assist with decision-making.

Based on the findings of the research, recommendations were made for nursing education and practice and suggestions for further nursing research.

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CHAPTER ONE

BACKGROUND PROBLEM AND PURPOSE

Introduction

Patients undergoing certain types of major elective surgery are frequently faced with a reasonable likelihood of blood loss requiring transfusion. The tainted blood scandal, resulting from the discovery in the 1970s and the 1980s of strains of hepatitis and HIV viruses in the national blood supply, and the subsequent Krever Commission of Inquiry (1993-1996) into the circumstances surrounding the contamination of the blood supply, have given rise to the development and implementation of alternative techniques and options to reduce the risk of acquiring blood borne infections through transfusion.

There is agreement that pre-operative autologous blood donation is a safe and effective method to reduce the risks of infection from blood-borne viruses. However, there is a paucity of research regarding the patient's perception and experience with autologous blood donation. In a recent Canadian comparison group study, Graham et al. (1999) found pre-operative autologous blood donors were positive about predonation but were unrealistic in their perceptions about receiving transfusions of blood from the general blood supply.

Determining patients' perceptions and experiences with autologous blood donation and other alternative techniques is therefore crucial to plan interventions that are not only cost effective but also meet patients' expectations. Therefore this descriptive study gave twelve pre-operative patients the opportunity, through semi-structured interviews, to articulate factors and resources used to make a decision to donate autologous blood.

Background

Blood: The Gift of Life

"The association of blood with life and vitality began in early history as indicated in the Old Testament text: 'Because the life of the flesh is in the blood and I have given it to you on the altar to make atonement for your souls: for it is the blood that maketh an atonement for the soul...' (Leviticus XVII: 11)" (Greenwaldt, 1997, p. 551). However, because the transfusion of blood involves the transplantation of human tissue from one individual to another, there are inherent risks, including a life-threatening incompatibility and disease transmission with receiving a blood transfusion. These inherent risks are well documented in Greenwaldt's review of the history of transfusion medicine (1997).

Perhaps the connection between blood transfusions and the "gift of life" over the years has created an impression to the public that the administration of blood is risk free. In Canada, for more than fifty years, blood transfusions have been instrumental in saving the lives of individuals who are experiencing serious blood loss during trauma, surgery, childbirth and other medical problems.

The Safety and Security of Blood: The Canadian Blood Supply System

The national blood supply system is an integral part of healthcare in Canada that had its origins with The Canadian Red Cross Society (CRCS). The CRCS was a federally chartered, private and not-for-profit humanitarian agency, established through federal legislation in 1909. Maintaining the blood supply began with the CRCS which initially had as its major objectives protection of and assistance with victims of conflict and

disaster, the prevention and alleviation of human suffering, the improvement of health and the prevention of disease.

Over the years The Canadian Blood System grew into a complex structure, comprised collectively of three main bodies. Maintaining the safety and security of the blood supply was the sole responsibility of the Canadian Red Cross Society (CRCS); funding was the responsibility of the Canadian Blood Agency (CBA) and the policymaking and regulatory functions were the responsibility of the Health Protection Branch of the Federal Government.

For close to half a century, the CRCS collected blood from donors through a voluntary blood donor program, tested donated blood for evidence of disease, and supplied blood to hospitals and clinics, with the costs borne by the CRCS through government grants. The CRCS blood donor program can be likened to that of an "insurance" policy where voluntary donors donate blood, which undergoes a rigorous screening and processing procedure and is then manufactured into four different products that can then be used during an illness, as prescribed by a physician, to help up to four different people.

The long and successful history of the CRCS in maintaining the blood supply was due in part to the more than 700,000 Canadians who responded tirelessly to the call for blood donors at the CRCS clinics, with more than 300,000 Canadians per year benefiting from the donations of the 'gift of life' (Picard 1998).

The 1970s and 1980s: The "Tainted Blood Scandal"

The public became aware, through media coverage in the early 1990s, of the concerns about the safety and integrity of the blood supply system with the discovery in

the 1970's and 1980's of strains of hepatitis and HIV contamination of the blood supply. There were media reports of scores of people who received the tainted blood with many becoming terminally ill. This became known as the "tainted blood scandal". The federal government responded to the public outcry for an investigation and in May 1993, the House of Commons committee called for a public inquiry into Canada's blood supply system. The federal government established a Commission of Inquiry led by Mr. Justice Horace Krever into the circumstances surrounding the contamination of the blood supply in Canada. The cumulative number of Canadians infected with the deadly HIV virus through blood contamination was estimated to be more than 2000 and it was estimated that approximately 60,000 persons were infected with the debilitating hepatitis C virus (HCV) (Picard, 1998).

1993-1996 The Krever Commission of Inquiry

The Krever Commission of Inquiry into the events surrounding the contamination of Canada's blood supply lasted for three years with testimonies from more than 400 witnesses and ended in December 1996. The Commission released an interim report in 1995 and the federal government released the final report in 1997 with recommendations for improving the safety and security of the national blood supply. One very significant decision made by the federal, provincial and territorial ministers of health in implementing the recommendations, was to revamp the structure of the Canadian Blood System. In 1998, The Canadian Blood Services (CBS) replaced the Canadian Red Cross Society (CRCS) as the new national body with a mandate to maintain the safety, security and integrity of Canada's blood supply.

The blood contamination scandal with its front-page news stories also had a major impact on the blood donor supply with an average 20% decrease in public donations of blood across Canada (CRCS, 1997). Fears of transmission of blood-borne viruses and the steady stream of media coverage of horror stories of persons infected with deadly viruses and the failings of the responsible bodies to take action led to a lack of public trust in the blood supply system, which in turn is considered to be the primary reason for the decrease in blood donors. The decrease in the donors led to a decrease in blood supply, which then impacted negatively on the ability of the CBS to respond to basic demands for blood. According to the CBS (1999) 5% of Canadians donate blood while 60% of Canadians will need blood or blood products before they reach the age of 72.

Reducing the Demand on the Blood Supply

One strategy identified to reduce the risk of transmission of a blood-borne infection was to reduce the amount of blood ordered for transfusion to patients during elective surgery. Changes to the policies and procedures that guide the ordering of blood and blood products by health care providers, can lead to a reduction in the use of blood products and reduce the demand on the blood supply. For example, the change in practice regarding HBT in one large urban tertiary care facility saw a decrease in HBT from 95% in 1992 for surgical patients to 17% for surgical patients in similar circumstances in 1997 (B. Muirhead, presentation, 1997). Reducing the number of blood transfusions ordered impacts positively on the supply of blood available for transfusion to others. With the creation of the new Canadian Blood Services (CBS) and in large part due to a strategic media campaign, the numbers of donors have since been increasing. For example, in one

prairie province, the number of blood donors increased from 50,000 in 1998 to 53,000 in 1999 (CBS, 1999).

Alternatives and Options to Receiving Homologous Blood Transfusions

Concerns with transmission of blood-borne infections such as HIV and Hepatitis C led to the development of new policies, procedures and practices with a goal to better serve the interest of the public. The public, prior to the tainted blood scandal, had been largely unaware of any issues related to blood transfusion or that other options were available. One alternative to receiving homologous blood (HBT) transfusions is autologous blood donation (ABD). ABD has been available through the CRCS for several decades. However, prior to 1988, collection of autologous blood was reserved for persons with rare blood types. Other methods that have been developed for minimizing the use of homologous transfusions include: (a) use of drugs to decrease bleeding e.g. desmopressin (b) use of erythropoietin to stimulate the bone marrow to produce red cells (c) use of blood salvage techniques and (d) use of acute normovolemic, hemodilution (Krever, 1995).

Autologous Blood Donation Programs

One recommendation made by Krever (1997) was that autologous blood donation (ABD) programs be established as one alternative to effectively avoid risks associated with homologous blood transfusions (HBT). The major risks associated with HBT are the transmission of blood-borne infections and hemolytic reactions. ABD refers to blood

donated by an individual for the purpose of transfusion back to the same individual.

Homologous blood donation (HBD) is defined as blood that has been placed in general supply of blood for the purpose of transfusion. Another term used for homologous blood is allogeneic blood.

There is agreement that ABD is a safe and effective method to avoid the risks associated with viral contamination (Stowell et al, 1990). Despite the acknowledgement that ABD is a safe alternative, Krever reported both a deficiency of autologous blood donation programs and an under-use of the existing programs with autologous blood collections representing less than two percent of the total blood collections (Krever, 1995). Therefore Krever recommended that more programs for pre-operative deposit of autologous blood be made available to patients throughout Canada. Informing patients of the option to predonate blood and providing written information about ABD well in advance of elective surgery, are also recommendations made by Krever (1995). The CBS Centre for the province in which the research study was undertaken indicates that requests for autologous blood donation have increased since the time of the Krever Commission of Inquiry. For example, in the year 2000, 410 requests were submitted through physicians with 347 patients accepted for the autologous blood donation (E. Giesbrecht, personal communication, May, 2001).

Benefits of Autologous Blood Donation

Krever (1997) identified seven major benefits of autologous blood transfusion that include: a) eliminates the risk of transmission of infectious diseases such as HIV, hepatitis, and other viruses that may escape screening procedures for homologous blood donations; b) reduces the risk of allergic, febrile, and hemolytic reactions which have the

potential to be fatal; c) eliminates the risk of alloimmunization to red cells, white cells and platelet antigens d) activates the bone marrow where blood cells are formed, allowing the patient's body to replace the blood lost during surgery more rapidly; e) benefits people who have rare blood types and for whom compatible blood is not easily available; f) decreases the demand on the homologous blood supply and g) may have a positive impact on transfusion practices due to the ready availability of autologous blood for surgical procedures.

Barriers to Establishing Autologous Blood Donation Programs

Autologous blood transfusion risks

Krever (1997) also identified possible reasons for the lack of development of autologous blood donation programs. One important reason identified by Krever is that autologous blood transfusion is not risk free. There are risks inherent in both autologous and homologous blood transfusions. These main risks include clerical error, circulatory volume overload and bacterial contamination. A clerical error can result in an incorrectly identified patient receiving blood or the incorrect blood being administered to a patient. The mismatch between the patient and the transfused blood can lead to a fatal hemolytic reaction. Jensen and Crosson (1996) report clerical and human errors as the leading cause of blood transfusion errors. Volume overload occurs when the patient's circulatory system is compromised in some way and not able to compensate for the volume of blood being transfused. A potentially lethal patient sepsis can occur if viable bacteria are already circulating in the donor at the time of donation, if viable bacteria are introduced at the time of venipuncture or if the collection bag for the blood is contaminated.

Other Barriers to Establishing Autologous Blood Donation Programs

Inclusion criteria, demographics

Other barriers identified by Krever (1997) that have contributed to an underdevelopment of ABD programs are the restrictive inclusion criteria for donating autologous blood. Until 1988, the CRCS restricted the collection of autologous blood to persons with rare blood types. Since 1988, the eligibility criteria for predonation have become less restrictive. Currently, the CBS has no age restriction and the person undergoing surgery must be in good health. There must also be a reasonable likelihood of blood loss requiring transfusion during the operative procedure.

Costs associated with autologous blood donation programs

Another reason may be a lack of financial resources to establish programs within the blood centres during times of fiscal restraint. The costs for establishing hospital-based programs would be absorbed by the hospital whereas currently hospitals in Canada receive blood "on demand" from the blood supply centers free of charge with costs being borne by the Canadian Blood Services through government grants. The research shows there are differing opinions about the costs that are associated with running autologous blood donation programs. On the one hand, the overall health care costs may be reduced if the patient avoids the adverse effects such as a hemolytic reaction or a blood-borne infection; on the other hand, the per-unit costs are greater for the autologous blood donation due to administrative costs associated with the collection and delivery of the autologous blood (Tretiak et al., 1996). For example, autologous blood is collected on an individual basis, while large numbers of units of blood for homologous blood

transfusions use are collected through blood donor clinics. The CBS has a policy that requires all unused autologous blood, even if it has not expired, to be discarded. This adds to the increased costs associated with autologous blood donation. Furthermore, the ratio of autologous blood donated to autologous blood used is frequently high which contributes negatively to the costs associated with autologous blood donation programs. For example, the ratio of autologous blood units donated to units transfused varied from 2.6 to one unit to 4.1 units to one unit respectively over the last three years at the study hospital. The higher costs associated with ABD may also be related to the fact that autologous blood donation clinics are located in large urban centers where major surgery is performed. Patients who wish to access the program are therefore required to travel to the ABD clinics at considerable personal cost.

Lack of Research into Public's Needs or Expectations for ABD Programs

Another contributing factor to the underdevelopment of autologous blood donation programs is the lack of nursing research exploring the patients' perceptions and experiences with autologous blood donation programs. Graham et al. (1999) in their Canadian study found patients were positive about the autologous blood predonation experience, but their perceptions about receiving blood transfusions were unrealistic. The study results reinforced the need for further research to determine whether other patients who donate autologous blood also have unrealistic perceptions about receiving homologous blood.

The Role of Nurses in Blood Supply Processes

Currently nurses play a pivotal role in several different aspects of the blood supply processes and nurses are well positioned to gather information surrounding the factors used by patients when making a decision to donate autologous blood. For example in blood donor clinics, nurses' responsibilities include the screening of potential donors to ensure the criteria for maintaining a safe blood supply are met; the monitoring of actual donors for adverse effects during the blood collection process and educating the public and health care professionals about blood and blood products and the services offered by the Canadian blood supply system. Nurses also play a critical role outside the boundaries of the Canadian Blood Services centers as the health care provider with responsibility in providing for the safe administration of blood and blood products, not only in acute care settings, but also in community clinics and at the patient's home. It is the researcher's contention that the benefits to the patient from the provision of quality nursing care must be demonstrated through published nursing research and conveyed to the public. For, according to Meleis, it is through "such public awareness and accountability that are the main pillars on which the discipline of nursing will rest" (Meleis, 1997, p. 426).

Statement of the Problem

In his final report, Krever (1997) recommended that more autologous blood donation programs be established. There is universal agreement that autologous blood donation is the safest form of transfusion. He also reported an under-use of existing programs. Autologous blood donation studies have focused on the technical, operational

and economic approaches related to blood transfusions from the physicians' perspective. There is a lack of published research exploring the perceptions and experiences of patients with autologous blood predonation. The research demonstrates that autologous is a safe alternative to homologous blood donation, but there is no consensus as to the cost-effectiveness of the technique. Currently information about autologous blood transfusion is conveyed to the public in two main ways: the media and physicians. Nurses are in key positions to act as a major resource for patients, but it is the writer's belief that nurses may not be fully aware that in their role as a resource, they may not be meeting the information needs and expectation of patients surrounding autologous blood donation.

Purpose of the Study

The intent of this descriptive study was to gain insight into the perceptions and experiences of surgical patients who predonated autologous blood. Patients undergoing major elective surgery are at risk of loss of blood requiring homologous transfusion. Preoperative autologous blood donation is one technique used to reduce the risk of transmission of blood-borne infections. The perspectives and experiences of the patients with autologous blood donation have not been adequately researched. Four components of Becker's Health Belief Model (1974) were examined as they relate to autologous blood predonation decision-making. It is hoped that this research will increase public awareness and assist with meeting their expectations of autologous blood donation programs. Another goal is to highlight the importance of further research so that

healthcare providers are able to plan for effective interventions regarding blood transfusion options for surgical patients.

Research Questions

The research questions addressed were:

- 1. How and from whom do persons learn about autologous blood donation and any other options or bloodless techniques used for persons undergoing elective surgery?
- 2. What are the factors used by persons when making a decision to donate autologous blood preoperatively?
- 3. What expectations (pre-operative, intra-operative, and post-operative) do persons have surrounding the autologous blood donation experience?
- 4. What decision would persons make regarding blood transfusion options if additional surgery was required in the future?

Conceptual Framework

The conceptual framework used for this research is Becker's (1974) Health Belief Model (HBM). The Health Belief Model postulates, "that health-seeking behaviour is influenced by a person's perception of a threat posed by a health problem and the value associated with actions" (Polit & Hungler, p. 104). Becker's (1974) framework has three major components: individual perceptions, modifying factors, and the likelihood of taking action (Appendix B). The HBM postulates that for an individual to take action to

avoid a disease, (for the purpose of this study, a blood-borne infection), an individual would need to believe (Becker, 1974, p. 3):

- i) That he/she was susceptible
- ii) That the occurrence of the disease would have at least moderate seriousness on some component of his/her life
- iii) That taking a particular action would be beneficial and outweigh the barriers.

The three components of the HBM were used to develop the semi-structured questionnaire as follows.

Individual Perceptions

In this study, perceived susceptibility refers to the perceived threat of acquiring a blood-borne infection through a transfusion. Patients undergoing specific types of elective surgery face the risk of loss of blood in an amount requiring replacement through transfusion. Traditionally the transfusion is administered with blood collected from the general blood supply. This perception may vary greatly among patients from the belief that there is a minimal risk to a real danger of acquiring viruses such as HIV or Hepatitis C. Perceived susceptibility and seriousness are at least partly dependent on knowledge of the risks associated with blood transfusions and knowledge of options available to avoid homologous transfusions. Participants were asked to describe information or explanations provided about bloodloss in relation to their surgery.

Modifying Factors

The HBM is comprised of two groups of modifying factors that influence the likelihood of taking action to avoid the perceived risk of susceptibility or seriousness associated with acquiring a blood-borne infection. The first group of factors includes demographic variables, sociopsychological, and knowledge or structural variables. Participants were asked questions in order to gather demographic data including their gender, age category, years of education, type of work, work status, type of surgery and blood transfusion and blood donation history. Sociopsychological data were not collected for the purposes of this study. Gathering demographic data "serves to condition both individual perceptions and the perceived benefits of preventive actions" (Becker, 1974, p. 6).

Knowledge is a structural variable identified as a modifying variable in Becker's (1974) HBM. Participants were asked questions about their prior awareness of autologous blood donation, the types of information provided about autologous blood donation and other options, and their past history with blood transfusion or donation to the general blood supply to gain insight into the influence knowledge had on their perception of risk associated with safety of the blood.

Cues to Action

In Becker's (1974) HBM, a cue to action refers to an instigating event in combination with perceived susceptibility and perceived benefits (minus barriers) that triggers an overt behaviour or action. Participants were asked questions

about how they first heard about autologous blood donation, past experiences with blood donation and transfusion and what was the main reason they chose to donate their own blood. The researcher wanted to identify whether family experiences, media coverage of the contamination of the blood supply or media coverage of changes to the blood supply system to make it safer served as cues to take action when faced with the risk of blood loss during the anticipated surgery.

This study will ultimately examine three components of the Health Belief Model as they relate to decision-making factors used to donate autologous blood: a) the individual perceptions of patients faced with the risk of blood loss requiring transfusion during elective surgery; b) the influence of demographic variables and knowledge in choosing autologous blood donation as an option to deal with the potential loss of blood; and c) the main factors that served to trigger the action to predonate autologous blood. This study was not designed to capture information about patients who did not choose or were not offered the option to donate autologous blood. However, participants were asked what action they would take regarding ABD if faced with elective surgery in the future. It is the researcher's intention that potential barriers to action would be identified through this question. By using the HBM, it is the researcher's contention that identification of factors, from the perception of the patient, used to predonate autologous blood would assist health care providers and policy makers to plan interventions and programs that would meet the needs and expectations of patients. It is also anticipated that future research would be conducted to gain further insight into patients' expectations and experiences with autologous blood donation.

Definitions

Autologous blood donation (ABD) refers to blood donated by an individual for the purpose of transfusion back to the same individual

Homologous blood transfusion (HBT) refers to the transfusion of blood that has been placed in general supply of blood for the purpose of transfusion

Allogeneic blood is another term for homologous blood

Alloimmunization refers to a transfusion complication in which the recipient of the transfusion reacts against donor antigens on the transfused red cells, white cells, platelets and proteins and for which the risk increases with the number of units transfused

Directed donation refers to a blood donation made by a donor chosen or known by the recipient.

Summary

This chapter provided the background information for the topic under examination, the decision-making factors used by patients to donate autologous blood prior to undergoing elective surgery. Four components of Becker's Health Belief Model were used as a conceptual framework to develop the research questions. The purposes of the research have been articulated.

CHAPTER TWO

REVIEW OF THE LITERATURE

Introduction

A review of the literature was undertaken to identify knowledge and issues related to autologous blood donation. Two types of literature reviews were considered. First were meta-analyses and annotated bibliographies regarding autologous blood donation and second was a review of research studies conducted into autologous blood donation including risk of blood-borne infections and error rates, cost-effectiveness, complications, reactions and benefits and patient perspectives. Computerized and hand searches were conducted. A plethora of quantitative studies have been conducted, however, there was a lack of qualitative studies available for review.

There are three well-established methods of obtaining autologous blood. One method is a preoperative donation of one to four units of blood. A second method is the perioperative blood salvage. A third method is the intra-operative normovolemic hemodilution. There has been a significant increase in research related to blood transfusion practices in the past decade. For example, The Autologous Transfusion Committee of the American Association of Blood Banks prepared an annotated bibliography of 60 articles from among the more than 300 articles published from 1991 to 1996 (Stowell et al., 1998). For the purposes of this research study, the literature review was limited to studies in which the autologous blood methods was for individuals who made a preoperative donation of one to four units of blood for their own transfusion.

Agency Reviews

The American National Blood Resource Education Program Expert Panel of the National Heart, Lung and Blood Institute (1990) indicated that advances in technology for testing blood and additional blood donor screening procedures have reduced the risk of transmitting disease. In addition, the implementation of the recommendations from the interim and final reports of the Krever Commission such as advances in technology for blood testing, use of alternative blood and bloodless techniques and use of autologous blood, continue to reduce the risks to the public related to blood transfusions (Health Canada, 1998).

Autologous blood is the safest option in reducing the risk of blood-borne infections and hemolytic reactions for the patients undergoing elective surgery with a reasonable likelihood of blood loss requiring transfusion (JAMA, 1990). Individuals who wish to predonate autologous blood must meet the eligibility criteria set by The Canadian Blood Services and the surgeon must complete a "Physician Request for Consideration for Autologous Transfusion" form and send it to the Canadian Blood Services for consideration of acceptance. The criteria to be considered for the autologous blood donation program include: patients must be slated for elective surgery for which there is a reasonable likelihood that transfusion will be needed, and the patient must be in good health, without current or serious health problems or low blood counts. Hemoglobin and hematocrit are closely monitored to ensure it is safe to continue to donate and to not be compromised while undergoing surgery.

Pre-operative autologous blood donation is not new and has been available to patients for more than two decades in Canada. Prior to 1988 the CRCS reserved

autologous blood donation for persons with rare blood disorders. Following the tainted blood scandal requests for ABD increased by 20% in one prairie province (E. Giesbrecht, personal communication, 1998). For the province where the study was conducted, approximately 325 individuals were accepted, on average, into the blood donor program per year for the past five years. The Canadian Blood Services (CBS, 1998) has written an information guide sheet for patients who choose autologous blood donation (Appendix A).

Patient Perspectives

During the past decade the health care system has undergone massive changes at a rapid rate. The patient of the modern health care system has also changed. Due to advances in communication and information sharing such as the Internet, patients have become more informed and more vocal regarding their expectations with respect to health care. However, within this modern health care system, patients are faced more than ever before with difficult choices surrounding treatment options.

The control over decision-making has traditionally been with the physician as a result of the structure of the health care system itself (Moloney & Paul, 1993). According to Moloney and Paul (1993) the past generation embraced security and authority, largely due to having suffered through major wars and a severe economic depression. In health care, this was reflected in their respect for the physician's counsel and advice, which they followed. However in sharp contrast to this past generation, the current generation seeks far more information (Degner, Sloan & Venkatesh, 1997); involvement (Guadagnoli &

Ward, 1998); and control (Feste & Anderson, 1995) over decisions surrounding their health care.

Strategies to meet the changing expectations of the patient and to provide better and more humane patient care have been a focus of the changes in health care. The care providers must also consider how their care impacts the patient from the perception of the patient. Patient satisfaction is one approach that involves asking patients, as recipients of a service, about their satisfaction with the quality of service provided. Patient satisfaction techniques seek to measure with some degree of precision the patient perception of the experiences as well as outcomes of the care received to better meet patients' needs (Shortell et al., 1995).

"Canadian data about patients' experiences" and "resources used" to make a decision about autologous blood donation are lacking (Graham et al., 1999, p. 990).

Therefore Graham et al. (1999) undertook a study to examine the patients' perceptions and experiences with autologous versus allogeneic transfusion. Patients' perceptions were measured quantitatively using a Likert scale questionnaire that also included open-ended questions. The study results showed autologous blood donation was a positive experience for the majority of the patients and patients would choose to donate again. It is also significant that Graham et al. found autologous blood donors overestimated their chances of receiving homologous blood had they not predonated.

Quantitative Studies

Several recent studies have been conducted regarding the use of autologous blood for elective surgical patients (AuBuchon, 1996; Birkmeyer, 1995; Farrer et al, 1997; Larocque et al, 1997; Keston & Enthoven, 1998). The research regarding use of ABD in

pre-operative patients most frequently cites orthopedic patients as the study sample. One reason is that joint (hip or knee) surgery has historically been associated with a high risk of blood loss requiring a transfusion. Another reason is the stable condition of the patients preoperatively which makes them excellent candidates for donation of autologous blood during the three to four weeks prior to surgery.

In a discussion paper, AuBuchon (1996) described analysis techniques to determine the cost-effectiveness of pre-operative ABD for orthopedic and cardiac surgeries that effected change in physician transfusion practices. The author used a decision analysis tree to help make appropriate choices for ABD for the patient and the physician, through the use of a quality-adjusted life year measure. Keston and Enthoven (1998) found the use of autologous blood transfusions in orthopedic patients to be safe for the patient and cost-effective for the health care system because the patients avoid the potential complications of hemolytic reaction and viral contamination from homologous transfusion.

Keston and Enthoven (1998) in another study found the average length of stay for orthopedic patients was decreased because there were fewer transfusion related complications with the ABD group of patients. Although the study results showed autologous blood predonation was more expensive than homologous blood donation these health benefits to the patients were greater with autologous predonation.

The administrative costs associated with autologous blood predonation are related to more complex procedures required for the collection of a unit of autologous blood preoperatively; for storage of the blood until the date of surgery and for the delivery of the autologous blood to the correct hospital on the correct day from the blood supply center.

In another ABD study conducted with orthopedic patients (scheduled for orthopedic hip and knee replacement), Birkmeyer et al. (1993) compared autologous blood donation to other more accepted medical practices such as transplant procedures, cardiac by-pass surgery and hemodialysis. The cost-effectiveness was measured as the cost per quality-adjusted year of life saved. On the basis of this, the cost-effectiveness ABD was found to be lower for an ABD than other practices. The authors also reported that the results for cost-effectiveness of ABD program could be improved through avoidance of over-collection and over-transfusion of autologous blood.

Another major reason for the higher cost of autologous blood is due to the small volume since it is collected on an individual basis which does not permit the lower costs associated with the larger scale collection of blood from a group of donors all at one time (Birkmeyer et al., 1993). An additional cost-related factor is the policy that requires CBS to discard any unused autologous blood even though the same rigorous testing process is conducted as for homologous donors. The rationale for discarding unused autologous blood relates to the fact that the criteria for homologous and autologous donors are not the same. Therefore unused autologous blood is not crossed-over into the general blood supply.

Several studies have been conducted to identify methods for predicting the reasonable likelihood of blood loss requiring transfusion for elective surgeries. The research shows it can be difficult to predict whether a transfusion may be needed. One example of this is Renner's (1992) study of pre-operative autologous blood donation in 612 hospitals where less than 60% of predonated products were administered to the patient-donors. Larocque, Gilbert and Brien (1997) found the use of a point-score system

to be effective for predicting the likelihood of blood transfusion after orthopedic (hip and knee) surgery. The predictors of transfusion included: hemoglobin, weight, type of arthroplasty and primary or revision surgery.

There is a lack of consistency in the transfusion policies and guidelines for crossmatch prior to surgery. For example, one hospital may have a policy that requires blood to be available for patients undergoing knee surgery, while other hospitals do not.

The variation in these guidelines and policies contributes to confusion for the patients who must rely on the surgeon's recommendation to be accepted for autologous blood donation. If a physician considers the reasonable likelihood of blood loss requiring transfusion to be high, the physician will then refer the patient to the ABD program and request that several units be predonated. Another physician, who considers the transfusion requirement to be very low, will likely not refer the patient or inform the patient of the option of autologous blood donation. There is also inconsistency among the physicians about the number of units that should be predonated prior to having surgery. The maximum number that can be predonated over the four-week period prior to surgery is four units because autologous blood expires in 35 days. Each donation of 450 ml of blood represents about ten percent of the patient's total blood volume. The body replaces the liquid portion of the blood or plasma in approximately 48 hours. The body replaces the red cells in approximately six to seven weeks. According to the CBS, if a patient has normal hemoglobin at the onset of predonation, two to four units may be collected safely before surgery.

"Unused" blood is another significant and costly issue with autologous blood because any unused autologous blood is discarded. This factor makes the predicting of which types of surgery require transfusion and the procedures regarding how much blood should be predonated even more important for accountable and cost effective decisionmaking.

"Unused autologous blood" can result from the cancellation of elective surgery which may occur for a variety of reasons beyond the control of the physician. Since the autologous blood may be stored for only 35 days, unless the patient's surgery is rescheduled within this time frame, the autologous blood will be discarded. The cancellation of elective surgery, due to the heavy demands on the health care system, occurs at a fairly high rate especially for orthopedic surgery because the patient is usually deemed to be medically stable. With the current practice, the orthopedic surgery patient is most likely to have donated autologous blood.

Another reason for the existence of "unused" autologous blood is that it may not be required during the surgery. Since unused blood is discarded, eliminating unnecessary autologous donations is important to make ABD programs cost effective.

A separate issue, but one that can be considered to be a disadvantage of autologous blood donation is whether the patient may become unnecessarily compromised if the hemoglobin is too low. The CBS has very strict criteria regarding the blood (hemoglobin and hematocrit) levels for patients who choose to donate their own blood to avoid a severe anemia. From two to four units of blood may be collected safely before surgery (CBS, 1999).

One Canadian study compared the cost of homologous and autologous blood transfusions. Tretiak, Laupacis, Riviere, McKerracher, Souetre and the Canadian Cost of Transfusion Study Group conducted the study in 1997. The authors reported on the costs

associated with the collection, production, distribution and delivery of ABD. The mean cost was found to be \$210 to transfuse one unit of homologous blood and \$338 for the transfusion of a unit of autologous blood (Tretiak et al., 1997). The authors attributed the difference in costs between the transfusions to the differences in collection costs between CRCS centers and hospitals and the costs of wastage for associated hospitals, for which 2% (of the total cost) was for homologous transfusion and 18% (of the total cost) was for autologous transfusion. A need for further research was identified to compare the cost-effectiveness of homologous transfusions with alternative methods and technologies (Tretiak et al. 1997).

The positive benefit of reduced chances of bacterial infections related to the use of autologous blood was found in a 1997 study conducted by Farrer, Sparks and Scott. The authors' prospective study examined 50 patients who were scheduled for abdominal aortic aneurysm repair. The variables measured included: amount of blood transfused (using three methods), homologous blood transfused (if required), discharge hemoglobin and estimated blood loss. The results of the study demonstrate that in patients undergoing abdominal aneurysm surgery, postoperative infections are much more likely to develop in those who require three to four units of homologous blood compared with those who receive autologous blood. In patients who receive more than four units of blood, the infection risks were similar for both study groups.

The positive benefits (i.e., decreased viral contamination and decreased risk of sepsis) of ABD may give the impression to potential autologous blood donors that transfusion of autologous blood is risk free. There has been little research done related to adverse reactions associated with autologous blood transfusion. Domen (1998) conducted

a retrospective study of complications associated with autologous blood transfusions (ABT). The results of this study showed that only mild febrile reactions occurred with predonated autologous blood for 0.16 percent of the total number of predonated ABT.

In the College of American Pathologists' Q-Probes study (1995), Renner et al. found a very low reaction rate related to ABT with urticarial reactions occurring in 0.0095 percent of transfusions and febrile reactions occurring in 0.1203 percent. There were no reports of reactions related to clerical error, bacterial contamination or hemolysis (Renner et al., 1995).

The potential for clerical error is a risk in both ABT and HBT. According to Jensen and Crosson (1996) and Mintz (1999), the leading cause of blood transfusion errors is clerical and human errors leading to the administration of blood to the wrong patient or the administration of the wrong blood to the intended recipient patient.

However when two types of similar in appearance blood products are in use, the risk for clerical error is increased, due to error in reading labels. Another potential cause for error is a lack of staff education regarding autologous blood and lack of communication that autologous blood for a patient is in the hospital and available for the surgery. This lack of awareness, combined with the similarities in appearance of the two types of blood, can lead to an autologous unit being given to the wrong patient or the autologous donor receiving the wrong blood. Goldman et al. (1997) found an error rate of one per149 units of predonated autologous blood collected, the error being associated with the shipping of autologous units between hospitals or blood centre, and improper labeling and preparation errors. Restoring public confidence in the Canadian Blood System by

ensuring that a safe donor-replacement program exists is a major thrust of the recommendations of the Krever (1997) report.

Another factor for consideration in autologous blood donation programs is the gender-related variation in transfusion practices. Stehling (1998) conducted a metaanalysis of research done to determine whether transfusion (all types of blood products) practices are influenced by patient gender. In her meta-analysis for autologous blood donation, Stehling found that autologous transfusion practices are influenced by the patient's gender. The studies showed a prevalence of iron deficiency anemia among women donors, but the diagnostic criteria employed for determining the anemia varied greatly. When hemoglobin alone was used to measure anemia in pre-menopausal women in the United States, prevalence of anemia was estimated to be 7.5 percent, but prevalence was 2.3 percent when diagnosis was based on multiple criteria. In males the prevalence was found to be 2.2 percent based on the hemoglobin alone and 0.2 percent respectively based on the multiple criteria. Therefore female patients are less likely to be able to donate sufficient autologous units to preclude homologous transfusion during elective surgery such as a CABG (Cardiac Arterial By-Pass Graft). The pre-operative administration of pharmacologic agents such as erythropoietin is effective for increasing erythropoiesis pre-operatively (Kantor, 1996). This would allow for an increased number of units to be donated and reduce the risk for exposure to homologous transfusion. It is therefore important that policies and procedures be in place to avoid inappropriate preoperative donation, which would increase the likelihood of homologous transfusion. Stehling concluded that the fact that females normally have lower hemoglobin levels

should be taken into consideration rather than gender per se, when determining the criteria for donation and or transfusion.

Synthesis of Findings of the Literature Review

The review of the literature demonstrates that the practices related to clinical autologous blood techniques are complex and multifactoral. There are studies to support autologous blood use as a safe option for selected patients. The research also demonstrates the need for more research to determine whether the use of predonated autologous blood is truly a cost-effective option when a comparison is made with other methods. The donor undergoing elective surgery may perceive the use of autologous blood to be the only option available, or may be unaware that homologous transfusions may still be required during surgery. The research shows that autologous blood transfusions are safer than homologous blood transfusions. However the public may be unaware of what the risks are besides viral contamination, with any blood transfusion options. The research shows that the number of blood donors overall has decreased since the tainted blood scandal erupted and therefore the public appears to be unclear about where the risk lies related to viral contamination and the blood supply. There is a lack of research that identifies what level of knowledge the public has about autologous blood donation programs. The public may not be aware of the inherent risks associated with either autologous or homologous blood transfusions when considering their transfusion options. Nurses play an important role in providing the patient with the appropriate information and are well positioned to provide information to meet the needs of the patient who is trying to make a decision about autologous blood donation prior to having

surgery. The nurse is also accountable for conducting research that will assist the patient with making difficult health care decisions in today's complex system.

Summary

A review of the literature related to autologous blood donation including risk of blood borne infections and error rates, cost-effectiveness, complications, reactions, benefits and patients' perspectives have been presented and discussed. Autologous blood donation is a safe and effective technique, available for patients undergoing selective types of elective surgery, to reduce the risk for homologous transfusion and thereby reduce the risk of blood borne infections. The cost-effectiveness of this technique has not been fully determined. Determining patients' perspectives is an essential component in planning appropriate intervention programs. There is a lack of research into patient perspectives regarding autologous blood donation.

CHAPTER THREE

RESEARCH METHODS

Introduction

A qualitative research method was used for this descriptive study to address the question "What are the factors used by preoperative patients when making a decision regarding autologous blood donation?" This chapter will include a description of the research approach, sample, data collection methods, the interview guide, data analysis procedures and ethical considerations.

Research Approach

Naturalist or qualitative designs are especially useful when little is known about a phenomenon. Sandelowski et al. (1989) describe Lincoln and Guba's (1985) set of beliefs as fundamental to conducting research in the naturalist paradigm. These beliefs include: "(a) reality is complex, constructed and ultimately subjective, (b) the research act is an interactive process in which the inquirer is ultimately inseparable from the subject of inquiry; and (c) truth is best achieved by initiating the encounter with subjects of inquiry in their natural environments naively, or without prior theorizing" (Ibid. p. 77).

The literature is replete with quantitative studies related to the development of safe, cost-effective alternatives to HBT. The major impetus for the research has been externally driven with the discovery of viral contamination of blood products, the subsequent blood supply system scandal and inquiry and recommendations from the

Krever Commission of Inquiry. There is no consensus among providers that adding more ABD programs will address the public's expectations for a safe blood supply system. The responsibility for a safe blood supply is a collective one that includes many different processes, a variety of health care professionals and the public. There is a lack of published nursing research describing the autologous blood donation experience from the perspectives and expectations of the blood donor. Therefore the proposed research design is well suited to the topic of investigation. The use of interviews allows for the provision of a full description by participants of the ABD experience. Interviews will be audio taped, transcribed verbatim and supplemented with notes to reflect the interview as accurately as possible. There are many considerations related to the blood donation and transfusion service and a large number of them pertain to the practice of nursing. Through the process of semi-structured interviews, the writer hopes to better understand such factors as how the sources of information influence decisions, under what conditions the decisions are being made, what motivates the person to make one decision over another and whether the decision would be the same under similar circumstances in the future. By describing these factors used by patients in this study, it is anticipated further research will be conducted that will lead to a practice by the health care providers, doctors and nurses that best meets the needs and expectations of the patient regarding blood transfusion decisions.

Sample

Sample Selection

A volunteer purposive sample was used to establish a sample constructed of twenty (n=20) subjects from an accessible population of approximately 325 individuals who predonate autologous blood per year in a Prairie province. Purposive or theoretical sampling is typically used for qualitative research to designate the potential study participants (Sandelowski, 1989). The sample size must be large enough to capture the richness of a wide range of perspectives and be as representative as possible, thus avoiding a sample that is too small or biased. According to Sandelowski, the actual number of subjects may not be able to be determined ahead of time, but the researcher must demonstrate knowledge of the types of persons who are able to provide the most useful information about the research topic.

Participants in the study had to meet inclusion criteria:

- i) Predonated at least one unit of autologous blood through the CBS
 Autologous Blood Donation Program
- ii) Elective surgery performed at the designated urban tertiary care hospital
- iii) 18 years of age or older
- iv) Able to speak and understand English
- v) Telephone in residence
- vi) Reside in city or area surrounding the autologous blood donation centre

The responsibility for informing the patient that an ABD program exists lies primarily with the physician. The patient must meet the eligibility for autologous

predonation criteria determined by the Canadian Blood Services Regional Centre (Appendix A).

Once the physician has determined that the patient is a potential candidate for ABD, the physician completes a "Request for Autologous Blood Donation" form and forwards the form to the CBS center. Persons who meet the eligibility criteria for the ABD then deposit their blood in one of two cities in the prairie province. The rationale for choosing the designated tertiary care institution for the study was based on the following assumptions. First, by designating the largest tertiary care institution in the province as the institution where patients underwent surgery; the majority of the approximately 300 individuals who predonate per year would be available to be approached as potential subjects for the study. Second, a large tertiary care facility would have a large population of patients undergoing a variety of types of elective surgery with the reasonable likelihood of blood loss requiring transfusion. Third, patients undergoing major elective surgery with the reasonable likelihood of blood loss requiring transfusion would require hospitalization for a minimum of one week and therefore able to be approached prior to discharge to participate in the study. Fourth, the patients would be able to recall in detail their experiences and expectations with autologous blood donation during the early preoperative phase. Limitations of the sampling technique lie in the inability to capture those persons who were informed about the ABD program and chose not to deposit autologous blood and those persons who chose alternatives to blood donation.

Sample Acquisition

Permission to access patients at the study hospital was obtained from the Research Impact Committee. A designated person with access to the data regarding surgical patients who had predonated autologous blood, determined a potential subject's suitability for participation in the study. This same person then approached the nurse in charge of the patient to ensure the remaining eligibility criteria were met. The individuals who met the eligibility criteria were invited to participate in the study and a research disclaimer was read to the individuals (Appendix C). Individuals who agreed to participate in the study completed a tear-off portion of the research disclaimer that was then collected by the designated person. The tear-off portions of the research disclaimer containing the patients' phone number and address were then placed in a confidential envelope and given to the study researcher. Upon receipt of the names the researcher arranged to meet with and interview the participants who agreed to join the study. At the onset of the meeting the researcher reviewed the research disclaimer.

Difficulty was encountered in acquiring the sample size as proposed. From the onset of data collection, September 14, 2000 until November 17, 2000, a total of four participants had entered the study from an accessible population of eleven patients who had predonated autologous blood during the same period of time. The researcher identified two reasons possibly contributing to the difficulty with sample acquisition. First, the assumption that the majority of autologous blood donor patients undergo surgery at the designated tertiary center was not correct. Data obtained after the study was underway indicated that the number of patients who donated autologous blood prior to having surgery at the designated hospital was less than thirty in the past two years

(Hospital report, 2000). Secondly, the assumption that the potential participants would all be approached to participate in the study prior to discharge was also incorrect. The designated person reported that several potential participants who met the initial eligibility criteria were discharged prior to being invited to participate in the study. To overcome the second problem approval was sought from the Human Ethics Secretariat to request a modification to the sample acquisition protocol. The protocol was modified so that when a potential participant met the inclusion criteria but was not able to be approached regarding the study due to either postoperative discomfort or due to being discharged, the patient was called at home. The patient was invited to participate in the study and the research disclaimer was read to the patient over the phone. A hard copy of the disclaimer was also provided. At the close of the data collection process, twelve participants had agreed to participate in the study from an accessible group of twenty-one patients who had predonated autologous blood prior to undergoing elective surgery at the designated hospital during the eight-month data collection period.

The Interview Setting

Once participants agreed to participate in the research study, they were given two choices regarding the setting for conducting the interview. The two choices included either the hospital setting prior to discharge or in a mutually agreed upon setting outside the hospital after discharge from the hospital. No interviews were conducted before participants indicated being well enough to undergo an interview. The interview questions were pilot tested to determine the approximate length of time needed for the

interview. The length of time for interviews ranged from forty minutes to one hour and fifteen minutes.

The decision to conduct interviews during the early postoperative phase was based on the assumption that the participants would be able to recall accurate details of the preoperative autologous blood donation experience and if administered, the details of postoperative transfusions.

Data Collection

In addition to the interview guide questions, a minimal number of demographic data were asked of the participants at the end of each interview (Appendix D). The rationale for collecting demographic information was two-fold. First, was to ensure that the inclusion criteria were met. Second was to capture specific data relevant to the nature of the research topic by summary of information about the sample. The qualitative data were gathered using the semi-structured interview guide (Appendix D). The interview questions were developed using the components of Becker's Health Belief Model (1974). By using the semi-structured interview guide, the researcher attempted to focus the discussion, but not to inhibit the participant from describing fully the experience with autologous blood donation. For example, questions were asked to gather data regarding past experiences with blood transfusions, current experience with autologous blood donation and the anticipated actions in relation to ABD, should the need for such a decision arise in the future. All interviews were tape-recorded. Additionally the researcher made supplemental notes regarding the participant's general demeanor and emotional responses throughout the interview. Throughout the interview, the researcher

used communication techniques such as perception checking to ensure that the participant understood the questions and the researcher understood the participant's responses.

Data Analysis

The analytic process entailed data preparation, data analysis and data interpretation (Sandelowski, 1995). First all taped interviews were transcribed verbatim. The demographic data were entered into SPSS for analysis of the participants' attributes and a description of the sample populations was completed. Data were compared to findings in the literature with respect to the sample for gender, age categories, years of education, location of residence, employment status, work type, type of surgery and blood transfusion / donation history.

Data analysis involved reading and rereading transcripts to obtain a sense of the whole, listening to the audiotapes to recall the feel of the interview and then extracting words, sentences and significant statements and phrases from the transcripts. The significant statements were then organized into categories. The researcher used strategies identified by Ammon-Gaberson and Piantanida to assist with generating results from the qualitative data in order to avoid the inexperienced researcher in "becoming bogged down" with the data analysis process (1988). They suggest strategies including generating the concepts (i.e. conceptual framework) as the researcher moves from the concrete to the abstract. Construal of data to allow for meaning beyond the individual data bits (i.e. over-concern with objectivity can become a barrier), clearly distinguishes between the data analysis and management of data (i.e. use of colour-coded index cards

to manage data); and balancing premature closure and overly delayed closure in the data analysis process.

The findings are presented in chapter four. In chapter five, the findings are compared to the conceptual framework, Becker's Health Belief Model (1974), the sample, the literature and the research questions.

Methodological Rigor

Reliability and Validity

"Establishing the rigor of their method is essential for all qualitative researchers" (Rose & Webb, p.556, 1998). Methodological rigor is required to ensure the results are valid and reliable, and therefore trustworthy. Rigor in analysis requires honesty in the data collection process (i.e. being present at the interview, listening to the tape, transcribing verbatim) and recognizing that in analyzing the transcripts (i.e. reading them more than once, assimilation, interpretation) there is always a certain amount of creative endeavour and therefore findings cannot be "translated entirely in terms of concrete language" (Rose & Webb, p. 561, 1998). Participants were called to seek clarification of data when transcriptions and supplemental notes were unclear. The consistency and transparency of the research process will be demonstrated in the format of the research report itself. Rigor was also achieved through clearly identifying the research goals, the data collection methods, the data analysis structure and the research findings. The computer disks containing the data related to the research study in addition to the interview audiotapes and original hard copies of the verbatim-transcribed interviews have been appropriately labeled and are stored in a secure location for a period of ten years.

The secure storage of all data is an important component of empirical research in order to both maintain the confidentiality at all times of the data and to allow access to the data for review at any time in the future.

Ethical Considerations

Prior to beginning the research study, ethical and access approval was obtained.

The Human Ethics Secretariat approved a modification to the sample recruitment protocol.

Informed Consent and Voluntary Participation

The participants were invited to participate in the research study by the designated person who used the research disclaimer to make the potential participants aware of the study purpose and that participation in the study was entirely voluntary (Appendix C). Participants received a hard copy of the research disclaimer. The researcher at the onset of the interview read the research disclaimer and reminded participants that participation in the study was voluntary. Participants were also informed that they had the right to refuse to answer any questions during the interview.

Position of Power

The researcher was on a leave of absence from the tertiary care facility during the period of the data collection for the research study. The researcher clearly articulated her role in the research as a student researcher in all components of communication with any individuals involved in the research project.

Confidentiality

The researcher did not have access to the patient record. The researcher conducted all the interviews. Each participant was assigned a numerical code to maintain confidentiality in transcribing and analyzing data. All identifiable data remain in a secure and locked compartment away from other research related data. The audiotapes and supplemental notes from the interviews have been stored in a secure manner. A clerical worker who is qualified to perform the task and is trustworthy was hired to transcribe interview tapes verbatim onto diskettes that were then securely stored. The researcher did the analysis of the data. The audio recorded tapes and the transcripts will be kept in a secure place for a period of seven to ten years to allow for validation of research findings with raw data.

Access to Gathered Data

Access to the gathered data (audiotapes, transcribed interviews and supplemental notes) was limited to the researcher, her thesis chairperson and the transcriber. All data that was made available to these two people was labeled by the participants' numerical code only.

Plans for Future Use of the Data

The data will be used only as described to the participants verbally, in the written invitation and in the written consent. In compliance with the PHIA Act (Privacy Health Information Act), the researcher will follow all the rules as outlined in the ethical approval and access committees to safeguard the participants' confidentiality when

considering the publication of the research study once the thesis has been defended. The researcher has an ethical obligation to share research findings with health care providers to enhance the development of healthy public policy and effective health care interventions.

What will be Revealed That is not Currently Known

There is a lack of published nursing research related to experiences and expectations of the autologous blood donation from the patient's perspective. The discovery of viral contamination of the blood supply with HIV, Hepatitis C and potential contamination of other viruses have led to a flurry of research related to the topic of blood transfusions. Much attention in this research has been given to the technical, cost and safety aspects of blood interventions from the perspective of the physician. Through this research, a better understanding will be gained related to the information needed by patients when making a decision about blood options prior to undergoing elective surgery, what role does or should the nurse play in providing this information and what additional research is needed to determine whether autologous blood clinics are meeting the needs of the public.

Potential Benefits to Participants

The opportunity to share and reflect upon the autologous blood donation experience was a potential benefit to participants. The participants may, through reflexivity, discover more about their own needs and expectations regarding blood

transfusion issues. The participants may also be clearer about their future decision surrounding blood transfusion should surgery be required in the future.

Burdens and Costs to Participants

There was no direct cost to the participants except transportation costs unless the participants (n=2) chose to have the interview in a location other than his or her home. Interviews involved approximately one hour of the participants' personal time. Any rescheduling of interviews was (n=1) done at the convenience of the study participant. The interviews were conducted during the participants' post-operative phase. The interviews were not conducted until participants expressed a level of comfort to engage. Interviews were conducted after discharge from the hospital when requested.

Risk to Participants

There was no anticipated risk to the study participants due to the nature of the research topic. However, if a participant would have disclosed a situation that would have given rise to an emotional response, the researcher would have provided emotional support and offer to terminate the interview or offer the opportunity for the participant to withdraw from the study if that would have been the participant's wish. This did not occur.

Risk to the Researcher

There is also mild risk to the researcher when conducting qualitative research in the field related to the researcher's personal safety. Paterson and Gregory's (unpublished, 1998) discussion paper outlines four components of a researcher safety protocol: assessment of the situation, preventive strategies, identifying and responding to threat and follow-up. The researcher was at a mild risk in this study related to the potential for conducting interviews in unfamiliar or unknown settings.

The researcher minimized personal safety risks when conducting interviews by:

- i) Being aware of any potential risks in the environment related to the location of the interview
- ii) Calling the participant to confirm the interview date and time, instructions as to the location of the residence prior to the interview
- iii) Informing the thesis Chairperson and /or family member of the expected length of time for the interview process and address for conducting the interview.
- iv) Making certain that the researcher's car was in good running order and taking appropriate precaution when parking the car

Summary

Sample selection, data collection, methods, data analysis procedures and ethical considerations for this descriptive study have been outlined. The findings are reviewed in the following chapters.

CHAPTER FOUR

FINDINGS

Introduction

The results that emerged from the data analysis are presented in this chapter. The findings are presented in two sections. First the sample attributes are presented as demographic data. This is followed by a presentation of the qualitative findings as categories and the themes that constitute them.

Sample Attributes

Demographic Data

Twenty-one patients pre-donated from two to four units of autologous blood prior to undergoing elective surgery at a large tertiary care hospital in the prairie provinces, during the eight-month data collection process.

All patients who had pre-donated autologous blood and who met the inclusion criteria (18 years of age or older, able to speak and understand English, had a telephone in residence, and resided in the city or the surrounding area) were invited to participate in the study by a designated person.

In accordance with the approved study protocol, patients were contacted prior to discharge from the hospital. However, several potential subjects were discharged from the hospital prior to being invited to participate. Therefore the study protocol for inviting patients into the study was modified with approval from the Human Ethics Secretariat.

The modification to the study protocol enabled the potential subjects to be contacted by

telephone after discharge in order to provide information about the study and to extend the invitation to participate in the study.

Twelve patients agreed to participate in the study. Interviews were conducted using the semi-structured interview guide (Appendix D). Seven participants were interviewed in the hospital setting prior to discharge and five were interviewed after discharge. Of the five patients who were interviewed after discharge from the hospital, three chose to be interviewed in their homes and two chose to be interviewed in public settings. The duration of the interviews ranged from approximately forty minutes to one hour. Eight participants resided in the city and four resided in rural areas.

The participants' gender, age category, years of education, employment status and work-type were noted as well as the type of surgery and blood donor and blood transfusion history. All names of study subjects were protected through use of an assigned numerical code.

Gender and Age Range

Of the 12 participants there were an equal number of women and men.

As shown in Table 1 (p. 54), two patients were between the ages of 18 and 39 years of age; four were in the 40 to 49 years age range; and six patients were between the ages of 50 and 69 years. To be eligible for the research project, potential participants were required to be 18 years of age or older. Three patients who had predonated autologous blood were ineligible due to age with the youngest being twelve years old.

Table 1
Age Range of Participants

Age Range	Number of Subjects	Percentage of Subjects
18 to 29 years	1	8%
30 to 39 years	1	8%
40 to 49 years	4	34%
50 to 59 years	3	25%
60 to 69 years	3	25%
Total	12	100%

Years of Education

The majority, 67% (n=8) of the participants indicated that they had from 13 to 18 years of education. Two participants indicated having 12 years of education and two participants reported having less than 12 years education.

Work-Type

The participants represented a variety of types of employment including: mechanic, clerical (retired), self-employed (n=2), engineer, counselor, statistical worker, nurse (direct care) (n=2), health care clerical, financial worker, and (retired) financial worker.

Employment Status

Of the 12 study subjects, seven indicated they were on a temporary sick leave due to undergoing surgery. One person who was self-employed indicated the need to continue to work during the postoperative recovery phase, two reported being retired and two indicated they were on a long term leave due to their illness.

Past Transfusion and Blood Donor History

The majority, 83% (n=10), of participants had no previous experience with blood transfusions.

The participant's blood donor history varied; with one subject donating to the general blood supply in the recent past, six donating in the distant past and four participants reporting no experience with blood donation. One person indicated having sold blood in the distant past in the USA.

Pre operative Autologous Blood Donation

The total number of units of autologous blood donated for the 12 study participants was 28 units. Eight patients each predonated two units of autologous blood and four patients each predonated three units of autologous blood.

Type of Surgery

Ten of twelve patients underwent either spinal (n=5) or liver (n=5) surgery. Of the remaining two participants, one patient had a hysterectomy and one patient had oral/neck surgery.

Autologous Blood (AB) Received Back

Seven of the 12 patients received back 13 of the 28 autologous blood units predonated for a ratio of 2.2:1 of autologous blood (AB) units donated to AB units transfused.

Of the five participants who underwent spinal surgery, three patients received back two units of autologous blood each and one was transfused with one unit for a total of seven units of autologous blood transfused. For the five participants who underwent liver surgery, one patient was transfused with three, one was transfused with two units, and one participant was transfused with one unit for a total of six units of autologous blood transfused (See Table 2).

Table 2
Autologous Blood Units Transfused Back per Type of Surgery Performed

Type of Surgery	AB Units Transfused Per Patient	Number of Patients Transfused	Total AB Units Transfused
Spinal	2	3	6
Spinal	1	1	1
Liver	3	1	3
Liver	2	1	2
Liver	1	1	1
		Total = 7 patients	Total = 13 AB units

Adjunct Therapies

Information was gathered about adjunctive therapies or treatments prescribed for the participants. Two therapies were identified: iron preparation and erthyropoietin.

Iron preparation

Pre-operative iron preparations replace iron stores needed for red cell development, energy and oxygen transport. Ten patients, five men and five women, reported that an iron preparation had been prescribed by their physician as an adjunctive therapy to donating autologous blood. One of the two patients who was not taking iron

had a pre-existing blood disorder for which taking iron would be contraindicated and the other patient had a hysterectomy for which there was less likelihood of blood loss requiring transfusion.

Erythropoietin (Eprex)

Erythropoietin is a hormone that optimizes low hematocrit levels and corrects anemia. Seven of 12 patients received erythropoietin injections pre-operatively which were administered to the patients approximately twice a week for three weeks prior to the surgery. The participants indicated that they were participants in a pre-operative Eprex Program through the Pre-Admission Clinic at the hospital where the surgery was being performed.

Each of the seven patients who was receiving erythropoietin was also taking an iron preparation. Of the seven patients, three patients received all donated units of blood and one patient received two of three units of autologous blood. Three of the seven patients (liver surgery n=1, spinal surgery n=1, and oral/neck n=1) were not transfused with autologous blood.

One spinal surgery participant, who had received erythropoietin and an iron preparation was transfused with the predonated autologous blood and intraoperative autologous blood through blood salvage.

Qualitative Findings

This section of Chapter Four presents the findings of analysis of the interview data. In generating the results from the interview data the researcher began by listening to each tape and reading each transcript and loosely coding significant phrases and words. The transcripts were then re-read several times and the coding process continued. For each research question, the text of each transcript was compared with that of the others as a whole noting similarities or differences both as a whole and in subgroups so that it would accurately portray the shared and unique findings of the research participants. Significant statements merged into themes during this process. Finally, the major categories became clear as the themes were reviewed.

The answers to the following research questions were sought in the data analysis:

- 1. How and from whom do persons learn about autologous blood donation and any other options or bloodless techniques as alternatives for persons undergoing elective surgery?
- 2. What are the factors used by persons to make a decision to donate autologous blood pre-operatively?
- 3. What expectations do persons have pre-operatively, intra-operatively and post-operatively surrounding the autologous blood donation experience?
- 4. What decision would persons make regarding autologous blood donation or other options if surgery was required in the future?

In response to the above research questions, four major categories emerged from the analysis of the transcripts: Preparing for Surgery: The likelihood of requiring a blood transfusion; Autologous blood donation: Dealing with anticipated loss of blood;

Autologous blood donation: The Intervention and Autologous blood donation outcomes: Future considerations. Each of these categories was developed through the identification of significant statements and themes.

The categories and themes identified were:

I Preparing for Surgery: The likelihood of requiring a blood transfusion

The role of the Surgeon

The Patient's Perceptions / Attitudes

II Autologous blood donation: Dealing with the anticipated loss of blood

The option of autologous blood donation

Past experience with autologous blood donation

Other options / adjunct therapies

Motivating factors in choosing autologous blood donation

III Autologous blood donation: The intervention

Past transfusion / donation experience

The appointments

The screening and manner of treatment by staff

The information provided

IV Autologous blood donation outcomes: Future Considerations

Blood donated, blood transfused

Future donation

Category I - Preparing for Surgery: The Likelihood of Requiring a Blood Transfusion

The questions asked about the participants' type of surgery and learning about potential blood loss during surgery led to the emergence of Preparing for Surgery: The Likelihood of Requiring a Blood Transfusion as a category. This category reflected the participants' thoughts upon hearing about the potential for blood loss during their specific types of surgery and undertook to answer research question one. Within this category, two themes emerged: the role of the physician in communicating to the participants the options to deal with reasonable likelihood for a blood transfusion during the planned surgery and participants' perceptions and attitudes towards the information provided by the surgeon regarding the potential for blood loss during surgery.

Role of Surgeon

All participants recalled that it was their surgeon, who during a pre-operative appointment raised the topic of blood loss and the likelihood of requiring transfusion during their surgery. Of the 12 participants, 11 reported that their surgeons had indicated a reasonable likelihood of requiring blood transfusion(s) with their type of elective surgery.

One participant, who was a nurse, indicated that while her surgeon did not anticipate requiring a transfusion for her type of surgery (hysterectomy); the surgeon did complete the autologous blood donation request form once she indicated she wanted to predonate.

Participants' Perceptions and Attitudes

Participants' comments reflected their perception of the information provided by the surgeon. These recollections showed different perceptions about their interpretation of the likelihood of requiring a transfusion based on their recollection of the information provided by the surgeon. Statements that reflected these different perceptions were:

Well, he [surgeon] said in all likelihood you will be needing blood...

Other participants commented on the normalcy of associated blood loss with their type of surgery.

[He said] There was a reasonable chance, yes but it was stressed that blood loss is common (with liver surgery).

[He said] Well this type of surgery [orthopedics] was considered to be the type for a high blood loss. Anything to do with orthopedics is usually as a rule high blood loss when they have to cut bone; that was brought to my attention.

He [surgeon] said it [reasonable likelihood of blood loss] was a possibility.

Two participants were registered nurses. Their background in nursing influenced their understanding about the potential for blood loss. This was reflected in their use of medical terminology and their understanding of the likelihood of blood loss.

I was told that the potential risk of blood loss was low for my surgery [oral/neck], *unless* the carotid artery was accidentally severed in removing the tumour because of the proximity to it and then the blood loss would be high.

Pamphlets I was given said *maybe* [blood loss and likelihood of requiring a transfusion]; but I wasn't given a percentage. Just that there was a possibility. The doctor certainly didn't feel that I would need it.

Category II - Autologous Blood Donation: Dealing with the Anticipated Loss of Blood

Questions were asked about the circumstances that led to the decision to predonate autologous blood. The reflections of the participants led to the emergence of the category: Dealing with the Anticipated Loss of Blood During Surgery. Participants' comments as to how they first heard about autologous blood donation and what motivated them to choose autologous blood donation prior to undergoing surgery relate to research questions one and two. Four themes emerged from this category: learning about autologous blood donation; past experiences with autologous blood donation, information on other options / therapies presented and motivating factors in making the decision to donate autologous blood. Several variables were identified that affected the participants' motivation to donate: the perceived benefits for ABD, safety concerns regarding the blood supply; and risks associated with receiving back their own blood.

The Option of Autologous Blood Donation

Generally the option of using ABD was first raised during a pre-operative visit at the surgeon's clinic. In the participants' memories, the surgeon or the nurse in the surgeon's office raised the topic of autologous blood donation.

The (surgeon) asked me my preference about autologous blood donation and whether I wanted to go that route (ABD).

I could receive blood from other donors; apart from that there was no other alternatives. I was told that the hospital had to have blood on hand because of the risk of blood loss. So it was either 'take somebody else's or there was time to donate my own', which the participant felt the surgeon preferred.

My doctor initiated everything, his nurse followed through.

The nurse asked if I wanted to give my own blood.

She [the nurse] actually suggested it.

The doctor brought the topic up. Even though my father had donated his own [blood], still, I did not initiate that. If he [the doctor] wants to, then I want to.

A registered nurse participant indicated that it was a question on the pre-admission form related to donating your own blood prior to planned surgery that alerted her to ABD as an option. One participant, also a registered nurse, stated that *she* was the one who initiated the question of ABD. "I asked the surgeon if I could donate my own blood and the surgeon said he did not know if the option was still available [for his area of specialty, oral surgery]".

Past Experiences with Autologous Blood Donation

Comments made by the majority of participants indicated some prior awareness of ABD. Some participants knew about ABD due to family or other persons' experiences. One participant's mother donated with orthopedic surgery, another's son-in-law donated for hip replacement surgery, a brother-in-law for heart by-pass surgery, a client in health care had predonated and so had somebody's father.

For other participants, their recollections were that they just *knew* about autologous blood donation with their comments, "Oh yes...on the streets...everybody talked about it". "I know about it, because I am a nurse". "Yes it's something we've known about for year and years".

Two participants who were unaware of ABD until presented with the option for this surgery, had undergone major surgery in the recent past. Both participants stated that they did not have the option of autologous blood donation presented to them for the

previous surgery. One participant described his recent past experience with surgery as follows:

One thing to mention, this is my second major operation [in recent past]. I wasn't even told about the opportunity to donate my own blood until I registered...two days before the operation. It was explained to me that I could have donated my own blood and apparently even in that operation there was a good chance of blood loss, but I didn't have the option then.

Other Options Presented and Adjunctive Therapies Prescribed

There are techniques other than ABD available to patients that reduce the risk of transmission of viruses through contaminated homologous blood; for example hemodilution and blood salvage. As well there are adjunct therapies that can be prescribed to improve the oxygen carrying capacity and red cell production. Generally, participants did not recall options, other than autologous blood donation, to deal with the anticipated loss of blood being presented by either the surgeon during the discussion of ABD or by the nurse at the surgeons' office. Ten of 12 participants reported that they had been prescribed an adjunctive therapy, an iron preparation, pre and post operatively to help build up their hemoglobin. Seven participants reported that after the decision was made to donate autologous blood they consented, through the Pre-Admission Clinic at the hospital where surgery was being undertaken, to participate in a Pre-operative Eprex program as an adjunctive therapy to ABD. Erythropoietin (Eprex) is a hormone to increase the rate of red cell production and to help reduce the risk of exposure to homologous blood.

Some participants had some recollection of being asked about the blood salvage technique and others recalled the discussion of hemodilution at the time of their surgery.

One patient recalled learning that blood salvage was used when she asked about her blood.

They said if two pints are not enough, will you accept this treatment [blood salvage] and you had to sign a paper to that effect. I was rather surprised, when I had finished the operation and I said did you use the blood I donated; no they said they didn't have to and I thought well I guess that's good. But then I realized after they had done this other method [blood salvage].

Two participants commented that they had been approached about another study involving the administration of an oxygen carrier therapy, but the criteria for eligibility were not met for their entry into the study.

Motivating Factors in Choosing to Donate Autologous Blood

Participants highlighted factors that motivated them to make a decision to donate autologous blood prior to the planned surgery. The main factors for deciding to predonate autologous blood identified by participants were the following: the surgeons' and or nurses' recommendation and the participants' belief that their blood was safer.

Recommendation from Surgeon and /or Nurse to Donate Autologous Blood

The participants' reflections indicated that the surgeon's recommendation to donate autologous blood influenced their decision. The participants generally did not have memories of specific rationale being presented with the recommendation.

Two participants stated "recovery time in using your own blood seems to be better, better than using some other person's blood," and "beneficial to donate my own blood because the healing factors are greater" were benefits pointed out.

The majority of participants indicated they made the decision because their surgeon suggested it.

So it was either take someone else's [blood] or there was the option to donate my own blood, which [the surgeon and nurse] preferred.

The doctor said, you are not forced to do this (ABD), I am just recommending it for you.

[The nurse] said it would be a good idea to donate my own blood if I needed a transfusion.

One participant undergoing liver surgery, from the 60 to 69 years age category, made comments of his respect for the authority of his surgeon "I said well, if you're recommending it, it couldn't come from any better recommendation" ... "I'm putting everything in your hands... I really had faith in this doctor, that was the big thing".

Safety: Concerns Regarding Transmission of Blood-Borne Viruses

The majority of participants did not recall the surgeon or nurse at the time of the recommendation discussing the avoidance of transmission of blood borne infections as the rationale for recommending autologous blood donation. In their recollections, the surgeons did not specifically discuss the autologous blood donation as a method to avoid the transmission of blood borne viruses nor was the degree of risk of transmission of viruses with homologous transfusion discussed.

For two participants, safety concerns were a definite motivating factor in choosing to donate autologous blood. For one participant, a registered nurse initiated the process to predonate blood and blood safety was in the forefront of her recollections. She stated "Fear [of blood from others]... I'm paranoid about blood period; I didn't even want to have my own blood taken in the past."

The majority of participants' reflections indicated that the possibility of getting blood borne viruses such as HIV and Hepatitis C from a transfusion of other peoples' blood was a concern. Generally their reflections did not indicate the degree of their concern or how much of a role the concerns played in their decision-making. The majority of participants did not initiate a discussion of their concerns over the safety of blood with their surgeon. A study participant, who is a nurse, demonstrated the lack of trust in the safety of the blood supply as follows:

Yes, [with respect to concerns about the safety of blood] it's not so much the handling of it, well I guess it is the handling of it too. But the chance of getting HIV, Hepatitis and other blood related diseases, I feel no one really wants to get...The way they say AIDS doesn't show up, AIDS could take ten years to show up and if somebody lies about a few things, then you get this tainted blood, so there's still the risk there.

Another participant talked about fears of infection without mentioning the term HIV:

To be honest with you, [receiving other peoples' blood] did kind of bother me, I did think about it while I was having the operation. I was hoping I didn't get some wild blood in me.

Another participant's knowledge about the viruses had stemmed from media coverage of the tainted blood scandal.

I suppose that (safety) sprung to mind initially. Well, I think there were more risks with other peoples' blood even though from the fallout, because it was publicized so much, and it was a few years ago and things are much safer now. However, they still stress there are the odd chances that things can go wrong... I just wanted to cut down on as many risks as I could [because of my present condition].

Distrust of the system was also shown is the following patients' comments:

It is easy to lie, the screening [for blood donors] does not pick it up... All you can do is attempt a good screening process, but it is no guarantee of accuracy because people will donate for their own reasons. Some people give because it makes them feel good whether they have been intimate with people or unfaithful to their spouse. They just don't want to say it. They weren't anticipating to read those questions, so they continue to pat themselves on the back, not realizing they are putting others at risk, and still go ahead and do it [donate blood]. This is humanity, we like to make ourselves look good that is the way it is.

I was kind of leery at first because of all the bad experiences that the blood services have had in the past, you know with HIV and those [diseases].

One patient indicated concern about blood safety was not apparent at first, but safety emerged as a concern in the discussion as indicated in his comments.

Not a large factor [transmission of blood borne viruses], but something I was definitely aware of. I think more the decision came; I mean I didn't want to receive other people's blood because of all those issues. This was one definite concern.

For another patient, the concerns arose from his personal experience, a sister who died from the transmission of a blood borne infection.

I didn't want to [get blood from others] you know. My sister died of Hepatitis C, from a transfusion she was a 'bleeder'.

One participant, a registered nurse, underwent a hysterectomy. In reflecting back over her situation, she did indicate that safety about blood was a concern. However her situation was unique from the other participants in the study because her type of surgery was not considered to have a reasonable likelihood for blood loss requiring transfusion. "The doctor certainly didn't feel that I would need it". The participant's background as a nurse and beliefs held about blood system influenced her decision to ask her surgeon to initiate the autologous blood donation process.

Her experience follows:

I had to fill out a sheet [pre-admission] and on the bottom it asked a yes/no question something along the line of, would you like to donate your own blood for your surgery. Originally, I said no in the beginning. Then I thought about it for a while and then I said this is a silly decision. I thought that if I had the opportunity to give my own [blood], why not give my own blood. So I phoned her [the surgeon] back and said yes I would like to give my own [blood]. So then I had to go back and have some blood work done and talked to the doctor and after that she filled the order for two units [of blood]... So I was surprised when she did it. I don't know why she did it because I think she didn't feel I needed it, but she ordered it... Yes [I have concerns about blood safety], I feel that in another 10 years down the road they are going to find something else, they always do, it never fails.

[This patient continued to elaborate about her fears of blood safety and the inherent risks in transfusing it back and possible errors or if something happens to your blood].

Another participant described how a past experience with surgery during the time of the "tainted blood scandal" played a role in her preparations for surgery.

I had to have emergency gynecological surgery about ten years ago, when I was in my twenties, I had a small hemorrhage two days after my surgery and the doctor wanted to give me a transfusion. Because of all the HIV *stuff* my mother was really upset that I needed blood. The doctor told her that she could either say 'goodbye' to her daughter now [i.e. from the hemorrhage] or possibly say 'goodbye' later [by getting a blood carrying disease from the transfusion].

Reduced Risks with Receiving Back Blood

Participants' comments regarding why they were motivated to use autologous blood donation reflected the "compatibility with their body" of receiving back their own blood. The subjects also made comments that their own blood was more homogeneous to their body.

It seemed more logical to receive back my own blood since [my body] is used to it. There wasn't going to be any reactions..." and "if I can have my own blood, I would certainly rather have my own blood; it is certainly going to match better.

The inherent risks associated with receiving homologous blood, such as hemolytic reaction were not raised.

Other patients' comments about receiving their own blood back reflected their concerns about their own vulnerability related to their pre-existing health problems as indicated by statements such as they did not want to "add to their present problems". One participant with a blood disorder was concerned about her preexisting blood disorder more than the safety of the blood supply.

I don't think [viruses] will happen again, with the new system... Even though my father had used his own blood for surgery, I still didn't want to, with my iron problem [disorder of blood]. I didn't feel like adding another problem even if [the risk] was a nothing percent. I still had doubts [about getting any blood] so I would just stick with what I had"... they had to do a lot of checking [because of my blood problem] and in the end I could [give 2 units of blood].

Category III - Autologous Blood Donation: The Intervention

The category, Autologous Blood Donation: The Intervention, emerged as the participants reflected at length on the actual donating of autologous blood which addressed the third research question. A number of themes emerged from participants' reflections of the positive and negative aspects of donating autologous blood. These included: previous experiences as a blood donor, experience with transfusions, the autologous blood donation experience including appointments (convenience, wait time, accessibility), the autologous blood screening and intervention and manner of treatment by staff, and information (written and verbal) provided.

Previous Experiences with Blood Donation and Transfusion

Ten of 12 participants had no previous experience with receiving blood transfusions. All participants indicated this was their first experience with autologous blood donation. The participants had either no experience (n=4) as a blood donor or experience in the distant past (n=6) and no comments were made that would indicate past experiences were a major influence on the decision to donate autologous blood.

One participant's reason for not donating at the blood donor clinics for the public in the past, "I was scared, pretty scared of needles" did not prevent him from making the decision to donate blood for his own use for this surgery, a reflection of his own vulnerability.

Some participants indicated that they were "told to wait after surgery before donating blood. However they never thought about doing it again like they "just got out of the habit". As they reflected on the question of past donation, comments were made that perhaps they ought to have donated blood more often, but no specific comments were made with respect to the "tainted blood scandal" in their comments about decisions to be or not to be a blood donor.

Blood Donation Appointments: Accessibility, Wait Time, Convenience

Accessibility was not perceived as a problem. All participants had access to a center for making autologous blood donations and no positive or negative comments of associated personal costs regarding attending the clinics for their weekly donations were offered. Eleven of 12 participants made their donations at the CBS Centre in the city where the surgery was being performed and one participant predonated autologous blood

at a satellite center closer to where she lived. Eleven participants who resided in the city or immediate surrounding area of the CBS Centre made many positive comments about the physical environment of the center, which is new facility, including: "an impressive, beautiful center"; "convenient and with parking spaces for donors", "beautiful building, accessible" and "they have the best coffee". Participants stated that once they made the decision to predonate autologous blood, the CBS contacted them to set up the appointments for predonation. "CBS called to say my appointment was on Wednesday at 1400 hours and I suppose if it was inconvenient I could have asked for Tuesday, because autologous blood clinics are held Tuesday and Wednesday".

Participants stated the length of time for appointments was not an issue.

One participant stated "I did not have a problem with the time" and another described the time as "excellent; I would sign in at 2:02 and be out by ten to three". Wait time for the initial appointment was identified as long by two participants who recalled having to wait "longer" for the first appointment until other factors, such as being a participant in another study or blood disorder were "checked out" and the "okay" was given to predonate.

The majority of participants were receiving erythropoietin injections twice a week in addition to the weekly autologous blood donation. The participants did not comment negatively with respect to the number of appointments required for these interventions.

Generally, the participants described the appointments as 'convenient', "flexible" and "accessible".

ABD Appointments: Screening Process and Manner of Treatment by Staff

Participants' recollections of the autologous blood donation intervention fell into two main areas: the screening done prior to the donation, and the intervention itself including manner of treatment by staff. Generally the participants described the screening procedure as "very thorough, I wouldn't have felt threatened with the screening", and that "much more screening than in the past was very impressive", or they "felt comfortable with all the testing and screening and all the questions they asked", and that the CBS are taking a lot more precautions which "set my mind at rest".

While some participants perceived the screening as very thorough and therefore positive, others found the screening to be "too long" and "intrusive, when you are getting back your own blood".

Manner of treatment by blood donor clinic staff also emerged in the participants' reflections in the autologous blood donation experience. The majority of participants described the nursing staff at the blood donor clinic as: "friendly", "very nice", "helpful", make you feel comfortable".

The autologous blood donation intervention was "no problem", "easy", "cautious", "efficient" from the perception of the majority of participants. One participant who commented that his fear of needles was a factor in not being a regular blood donor, had a very positive experience with the donation. He described the experience in this way:

I never donated in the past because I was pretty scared of a needle; that was the main thing I had a big operation two years ago and I had transfusions then. But I did not donate blood, I had not heard of it before this time. This is all brand new to me; I didn't know what I was doing. But this was very easy; it's like eating cake.

Three participants had each had one experience that was not satisfactory for them.

One participant's description of an incident reflected her expectation that this should not have happened.

I wound up with a massive bruise on my arm... I blame the ... nurse for that; I even got a bruise on my fingertip from the hematocrit, it seemed like the staff was new.

Another participant described her initial encounter as:

They were doing the blood testing and they were training a new nurse, and [one] did the blood test and told me what the blood type was. I said 'no that's wrong' and x said this is right and the woman behind said this is right... so I had to phone my doctor, because I wasn't going to keep arguing.

A third participant stated this:

I was supposed to give two units [of blood], but my first unit was wasted. It had to be thrown because there was too much anticoagulant in the bag for the amount of blood collected. Because, there was too much burning in my arm and the needle was hurting my arm too much since it was improperly placed, I started to faint. So they stopped the blood collection. A week later I donated another blood unit and then my surgery got postponed. So I was able to go down and give a second unit after all.

Information Provided During the Autologous Blood Donation Intervention

Participants reflected on sources and resources for learning about autologous blood donation. Recollections included the provider of information (sources/resources) and the types of information provided. Questions were asked as cues to identify other areas of information that were provided throughout the autologous donation experience.

Health care professionals, nurses and the participants' surgeons, played a role as a resource for the participants in providing information to prepare participants for the autologous blood donation experience. Participants' recollections of the surgeons' role in providing information was that surgeons "recommended autologous blood donation"

and "identified the reasonable likelihood of requiring a blood transfusion". Participants' recollections of the nurses at the surgeons' office, the nurses at the pre-admission clinic and nurses at the blood donation center all played a major role in providing written and verbal information and in answering their questions and concerns as indicated in the following statements:

Nurses at the donor clinic explained it [autologous blood donation] to me very well... very well informed, the best I could be, they [nurses] went over it very carefully and made sure if you had any questions you could answer them.

Once I had the consultation with the physician, she [the nurse at CBS] dealt with me and the information provided was very good. I felt as though they were looking after me.

The surgeon initiated the autologous donation and then the nurse [at surgeon's office] followed through... the nurse told me what would be happening and what procedures would be done. The nurses at the CBS said I could call them back [if I had questions]. At first, I couldn't think of anything then but when I went back the following week there were a couple of questions, but they were able to answer.

The surgeon's nurse set it up, then another nurse from the hospital contacted me (pre-admission) and then I went to the "Red Cross" [CBS] who provided information. As well, the nurse at the hospital, the blood-coordinating nurse was really good and in fact I did phone her at night one night and she phoned me right back.

One participant who initiated the process for the autologous blood donation because of her own concerns about safety described the role played by the nurses at the blood donor clinic as "I learned a lot, I asked them lots of questions. It became less scary. I learned to trust a bit more".

The participants received both pamphlets and verbal information about autologous blood donation. For the majority of participants the explanations and /or

information provided was perceived as "very good" and "sufficient". However the information provided in the perception of one participant "wasn't enough, it's one of those things you take for granted, you just trust the system isn't going to fail you."

This participant elaborated further about his attitudes towards the information provided. The actions of using the Internet to gain additional information reflect a lack of trust in the system and the need to be informed.

So I got a little bit here and a little bit there. I trusted my doctor who has a very good bedside manner, but who did not really give me much information on the blood itself it [the information] was more to do with the actual surgery. I did my own research [on the internet] after it [autologous blood donation] was mentioned [by the doctor] and sort of followed up on it. I think probably [there should be] a little more information, maybe like a small manual might be better than pamphlets because people have a tendency to chuck these things; but people should be expected to read the information and to ask a series of questions. I was asked if I had any questions, but you are reading information from a lot of sources; you know I got pamphlets on this and pamphlets on that.... It's a bit much to swallow when you are not sure what to congeal... you've got to understand that as laymen we are new to this... when you (health care professionals) do this all the time, you assume people have the same understanding.

Additional questions were asked of participants to further explore the types of information that may have been provided but not shared in the participants' recollections on the information and explanations provided about autologous blood donation. Areas covered in these questions included: awareness of risks or side effects associated with blood transfusion, understanding of what would happen to unused autologous blood and the possibility of requiring more transfusions than the number of autologous units donated.

Recollections of Participants of Information Provided Regarding Risks / Side Effects Associated with Transfusions

The majority of participants did not recall discussions about risks or side effects associated with receiving back their own blood. The professional background of two participants who are registered nurses played a role their level of knowledge or understanding of risk of clerical error associated with blood transfusions. One nurse participant, who did not require transfusion, describes her concerns of risk for error, when she was admitted to the hospital.

When I got to the hospital, I found the staff was very unfamiliar with it [autologous blood]. Everyone I spoke to didn't know; when I came in with the cards [from the blood donor clinic] what to do with the cards and when I gave it to the nurse, she didn't know what to do with them. The nurse said there was an order to cross-match and I said that I had my own blood already. And there are a few things like that, that went on, but I was in a miserable mood. For example, the CBS said make sure that when they do the comparisons of your name band and the blood you donated, that they use your middle initial, that's important. Then when my addressograph came it did not have my middle initial on it.

Recollections of Participants Regarding Unused Units of Donated Autologous Blood

The questions regarding unused autologous blood included discussion of the expiry date and the disposal of unused autologous blood. The majority of the participants' comments indicated an awareness that donated blood had an expiry date; but they could not recall hearing about the actual number of days the blood could be kept. The participants comments about unused autologous blood were the following: "I don't know, I assume they dumped it by now", "they threw it out?", "they can't use it because I have cancer", "they use the plasma for other people", "can't use it because it is whole blood"

and "they don't use it at all, because it isn't screened in the same way" all of which indicate a lack of understanding about what happens to the autologous blood.

Recollections By Participants Regarding Being Transfused With Blood Donated from Other People

Participants' responses to the question of possibly requiring more transfusion than available through autologous donation raised topics such as consent for transfusion of homologous blood (blood from others) and use of alternative techniques such as blood salvage and hemodilution.

Some participants' recollections were that no discussion had taken place as reflected in the following statements:

It was not discussed at all, if my doctor thought I would need more, I would have donated more.

I didn't really think about this, I figured two units would be enough. But if worse came to worse, I would go to the blood bank or use saline solution.

It was never discussed, but if I had needed more blood than I had predonated, I would have taken it.

Other participants' recollections were that discussions had occurred and they had expressed their agreement verbally to using blood donated from others if it could not be avoided as follows:

Well, they said I couldn't give more than three units. They said they might have to use the blood on the shelf as well. I didn't want to [use other's blood] you know unless I had to.

I didn't want them to be stuck if more than two units were needed. When you are faced with death, 'what are you going to pick?' You are going to pick getting the blood from others.

Other participants' recollections were that they had given written consent to receive transfusions of blood donated from other people as stated in the following:

I had to sign a paper saying that if they needed a third pint or whatever that I would accept it. I probably would be happy to receive it at that point or informed [of it].

I did [sign a consent]. In fact, I initiated the discussion with the surgeon. I understood that requiring more blood might be impossible to avoid; but I didn't want to tie his hands either. In the event that something [like hemorrhage] does happen, I don't want to die then because there was no blood. What we decided was that they would have more of my blood type on standby, but they were to do everything possible to avoid it.

Category IV - Autologous Blood Donation Outcomes and Future Considerations

When participants were asked questions regarding the number of units of autologous blood they had received and actions they would take if surgery were required in the future, the final category Autologous Blood Donation Outcomes and Future Considerations emerged. This category encompassed two themes, as the participants recalled personal thoughts about autologous blood donation and future considerations.

Autologous Blood Donation Outcomes

The 12 participants donated a total of 28 units of autologous blood, and received back a total of 13 units, for a ratio 2.2: 1 for units donated to autologous units transfusions. Adjunct therapies, iron preparation (n=10) and erythropoietin (n=7) were

prescribed for the majority of participants. None of the 12 participants required transfusions of homologous blood (blood from the general blood supply). Several participants recalled that blood salvage and hemodilution were options presented at the time of the surgery. One participant commented that blood salvage had been used during her orthopedic surgery.

Participants indicated no major changes in the date of surgery occurred once the autologous donation process had begun. One participant indicated there was not sufficient time for the planned number of donations prior to the date of surgery, "they were going to try and get three units, but with the time factor, so I gave two".

Seven of 12 participants were transfused with one to three units of autologous blood per participant. Participants indicated that the autologous transfusions were administered either during the operating/recovery room phase or during the postoperative phase of their hospitalization. Participants (n=5) who were transfused during the operating/recovery phase were unable recall being transfused and therefore were not able to identify whether any side effects from the transfusion(s) had occurred. None were reported to the participants. The participants' comments generally reflected that they had been told whether or not they had received back their own blood. However, one participant did not express with certainty that she had received her blood back as indicated in her statement that it was her 'understanding' that her blood had been transfused back during surgery.

Another participant also indicated that he was not sure what techniques or options were used to manage blood loss in his statement:

I don't know if they used that [blood salvage]. I don't think they did because they used my blood because it was there. I remember seeing the blood hanging after surgery when I was in the recovery room.

Two participants' autologous transfusions were administered in the post-operative phase due to their surgeons' concerns about their hemoglobin and blood pressure following their spinal surgeries. Significant differences in perceptions regarding safety precautions used by the nursing staff during the transfusions existed between the recollections of these two participants in their comments "nothing special" and " very cautious, two nurses double checked everything". Neither participant recalled any side effects happening during the autologous blood transfusions in their statements as follows:

One week later [after spinal surgery] my hemoglobin was down and they asked me if I wanted my blood back. I said, 'Why not' because apparently it's no good after. I don't know how long it's good for, so I took the two units back.

About 48 hours after my [spinal] surgery, my hemoglobin was down which they said was normal. However, it was my blood pressure that went too low, to '70 something'. So they thought they would give me the two pints back.

Future Considerations Regarding Blood Donations

Participants were asked whether autologous blood donation would be their choice to manage a potential blood loss if surgery were required in the future. Generally, participants indicated that autologous blood donation would be considered for use "definitely", "definitely recommend it to everyone, save the 'blood bank' for people who really need it in emergencies". One participant who would use autologous blood donation again stated, "there also needs to be more bloodless surgery techniques

available". Two participants identified "more and more psychological support about the decisions to prepare for surgery", and "information provided to patients generally in the health care system" as areas for improvement. One participant's comment indicated she would trust her physician's judgment when making a decision to predonate blood if future surgery was required. The participant stated:

I would ask the doctor if there was a chance of bleeding and if he recommended it (autologous blood donation), I would do it. If he said no, I wouldn't. I trust him.

Overall, participants' reflections of their autologous blood donation experience in retrospect revealed a positive experience with responses which either "met" or "exceeded" their expectations. Two participants who had never been a blood donor in the past, expressed that they were now going to see if they "could become a donor in the future" if their health permitted it.

Areas identified in participants' reflections as not satisfactorily answered included directed donations and disposal of unused autologous blood. The questions surrounding directed donations from family members were seen in their eyes as a safe alternative to receiving blood from persons not known to them. Several participants raised directed donation as an option they would like to see used more widely. One participant indicated that he would predonate again, but he also believed that he should have been able to use his wife's blood in his statement:

I would donate again. But, what I didn't understand is why someone couldn't donate just for me... It didn't make sense to me, my wife does in there, and you don't know whose getting whose blood. Why couldn't I take a unit from her... we have the same blood type.

Another participant had asked if his daughter could donate for him:

I asked if my daughter could donate blood for me, I was curious as to why this is not acceptable.

A final participant, who lost a family member due to Hepatitis C following a transfusion, also wanted to have a family member donate blood as indicated in the following statement:

I wanted to have my daughter donate for me. I had a sister who died of Hepatitis C from a transfusion. She was a bleeder.

Several participants saw the discarding of unused blood as not being cost effective. One participant whose background as a nurse may have influenced her concerns and awareness of the costs associated with autologous blood when compared to homologous blood use, questioned the cost effectiveness of destroying all unused units of autologous blood with her comment:

I would definitely predonate again, but they should be able to make use of left over autologous blood. If the screening is the same, why can't they use it again, especially since it [autologous blood donation] is such an expensive procedure already?

Summary

The study sample attributes and qualitative data analysis have been presented in this chapter. Twelve patients undergoing elective surgery were interviewed about their experiences with preoperative autologous blood donation.

The study group was comprised of men and women, the majority being over 40 years of age, with different levels of education and who have been engaged in a wide variety of types of work. The majority of participants underwent two types of surgery, spinal and liver. The ratio of autologous blood donated to autologous blood transfused back was 2.2:1. The majority of the study group was receiving iron preparations and erythropoietin as adjunctive therapies to ABD.

Four major categories emerged from the thematic analysis of the transcripts.

Issues of trust of health care providers and the health care system were interwoven throughout their reflections and perceptions.

The first category, Preparing for Surgery: the likelihood of requiring a blood transfusion, emerged as the participants reflected on the role played by the surgeon in presenting the possibility of a transfusion and the participants' perception of the risk of blood loss.

The second category, Autologous Blood Donation: Dealing with the anticipated blood loss, emerged as participants answered questions about how they first heard about autologous blood donation, past experiences with this option, other options considered and motivating factors in making the decision to predonate autologous blood.

The third category, Autologous Blood Donation: The intervention, emerged as participants reflected retrospectively about the autologous blood donation appointments,

ambiance, manner of treatment, information provided and past personal experiences with either blood donation or transfusion.

The final category, Autologous Blood Donation Outcomes and Future

Considerations emerged as participants discussed the outcomes of their experience with

autologous blood donation and their expectations for the future.

CHAPTER FIVE

DISCUSSION OF THE FINDINGS

Introduction

This final chapter examines the relationship of the findings to the literature, the research questions, and the conceptual framework, that is Becker's Health Belief Model (1974). The purpose of the discussion is to discover the meaning of the findings, to draw conclusions from the research study and to identify gaps in the domain. Implications for nurses and other health care providers and suggestions for further research are also presented.

Relationship of the Findings to the Sample

Sample Size and Type of Elective Surgery Performed

The researcher made certain assumptions regarding the accessible population to achieve the goal of 20 participants for sample size. The largest tertiary care facility in the province, which was used for the study setting, performs approximately 10,000 inpatient procedures per year (Annual Report, 1999-2000). The first assumption made was that this facility would provide a suitable accessible population upon which to draw in order to conduct the research study. Second, the assumption was made that the majority of the approximately 300 individuals per year who participate in autologous blood donation programs in this province would undergo surgery at the designated tertiary care facility.

Therefore, the researcher's expectation was that a sample size of 20, who underwent a variety of types of elective surgeries, would be an achievable goal.

Sample Size

A sample size of 12 participants was acquired at the end of eight months recruitment. The majority of the group had two types of surgeries: five had spinal surgery and five had liver surgery. A total of 21 elective surgery patients were autologous donors at the designated study facility during the eight-month period of the data collection process.

Type of Surgery

One factor that may have contributed to the difficulty in achieving the desired sample size is a decrease in the number and type of orthopedic surgeries performed at the study hospital. Orthopedic (hip and knee) procedures have a reasonable likelihood of blood loss requiring transfusion. The researcher did not have access to the database for the numbers and types of surgeries conducted at the study facility. There has, however, been a restructuring of health care over the past three years with the establishment of regional health authorities that impacted on the number and types of surgeries performed at the study facility.

The change in types of surgeries performed at the facility may have also contributed to a smaller number of patients undergoing elective surgery who met the requirements for autologous blood donation. For example, at this facility, the number of patients who were transfused with autologous blood decreased from 26 in 1998/1999 to 18 patients in 1999/2000. These numbers do not indicate the total number of patients who were autologous blood donors nor those who did not receive their blood, nor does it

reflect changes in practice that may have been made by physicians in making decisions with respect to transfusing.

Therefore, while there were unanticipated difficulties in achieving the desired sample size and variation in type of surgery; number of participants (n=12) reflected 57% of the accessible population (n=21) at the designated facility during the data collection period.

Sample Gender

The study sample was comprised an equal number of women to men. Stehling's (1998) meta-analysis of research into the influence of gender on autologous blood donation practices showed a prevalence of iron deficiency anemia among female donors that made them ineligible for predonation in some instances and in other instances more at risk for homologous transfusion during elective surgery following autologous donation. According to Stehling, the criteria for defining and measuring anemia varied greatly among programs. The fact that there was an equal ratio of women to men in the study may have been influenced by the CBS policy that states the patient's hemoglobin must be close to normal and iron supplements must be prescribed during the period of the blood donation (personal communication, CBS 1999). In the study sample, 67% of the women had been prescribed iron supplements during the preoperative phase and 100% of the men.

Age Category

The Canadian Blood Services limits the age for homologous blood donation to between 17 and 60 years of age for first time donors and between 17 and 70 years of age for donors who have donated within the past two years (CBS Pamphlet, 1999). The CBS does not have an age limit for autologous blood donation (E. Giesbrecht, personal communication, 1999). The inclusion criteria for this study required individuals to be 18 years of age or greater. There was a wide variation in the age categories of the sample, with participants representing an age range from 18 to 69 years. There were three patients who predonated autologous blood between the ages of 12 and 16 years who were ineligible for the study. Since health problems usually develop in later years, it is not surprising that 50% (6 of 12) of the participants were from the 50 to 59 and 60 to 69 age range categories.

Age Category, Years of Education, Work-Type

The majority (67%) of the participants had 13 to 18 years of education and represented a variety of work-types, both professional and nonprofessional. Two participants were over 50 years of age and had less than 12 years of education and reported being self-employed. It is not unanticipated that the participants with the least number of years of education were from the older age categories and may have had to create their own employment opportunities. All of the participants in the 40 to 49 years age category were employed as professionals. Two were nurses, which may have been an influencing factor in their decision-making surrounding autologous blood donation. The number of years of education may be a determining factor in the demand for autologous

blood donation programs as individuals who are now in the 40 to 49 years age category age and encounter health problems.

Past Experience as an Autologous Blood Donor

Several participants had limited familiarity with autologous blood donation through the experience of family members or friends who had predonated autologous blood. None of the participants had donated autologous blood in the past. Although having no prior personal experience was not required for participation in the study, it was beneficial to the researcher to have a homogeneous group with no prior experience for the purposes of this descriptive study, especially given the sample size.

Relationship of the Findings to the Research Questions

This section of the chapter allows the researcher to move beyond the findings and address whether the research questions were answered. Each research question is presented separately in relation to the findings from the analysis of the interview data.

The First Research Question

Participants were asked questions about how and from whom they had learned about autologous blood donation or other options or alternatives such as bloodless surgery. The discussion of this research question consists of three components: did the participants know about autologous blood donation prior to this surgical event; how was the topic of blood loss communicated; how and from whom did the participants learn

about autologous blood donation for this surgery and any other options or bloodless techniques that could be considered for this surgery.

Prior Awareness of Autologous Blood Donation

The participants had no prior personal experience with autologous blood donation. The CBS has offered autologous blood donation to individuals undergoing certain types of surgery, since the 1980s (verbal communication, CBS, Winnipeg Centre, 1999). Prior to the 1980s, only persons with rare blood types benefited from autologous blood donation (Krever, 1995).

Approximately 300 individuals per years are accepted for autologous blood donation in the study province. With respect to the participants' knowledge of autologous blood donation prior to this surgery, none of the twelve participants in the study had prior personal experience with autologous blood donation. When the participants were asked how they first learned about autologous blood donation, most had some prior awareness that donating one's own blood could be done before surgery. Most participants did not use the term *autologous* in their reflections during the interview process, but they understood that autologous referred to donating blood for personal use later. The researcher avoided using the term *autologous* unless it was used in conjunction with the definition. Their awareness of autologous blood donation stemmed from relatives or others who had used their own blood for surgery.

Others were even less specific about how they knew, but it can be deduced from their comments "it is out there on the streets" or "because I am a nurse" that they had heard of autologous donation. The participants whose family members used autologous

blood donation in the past, made no comments that indicated their own autologous blood donation was different from that of their relatives. What was not clearly answered was whether the use of ABD by the participants' relatives or any prior awareness of ABD influenced study participants' decision to donate autologous blood. Gathering data in relation to this aspect would be considered in a future study design. One participant specifically indicated that her father's decision to use his own blood was not a motivating factor to donate her own. For this participant, it was her medical problem and the trust in the surgeon's judgment regarding the need for donation that had the greatest impact on her decision to donate.

The Likelihood of Blood Loss During Surgery

The participants were asked questions regarding how the topic of blood loss requiring transfusion was approached for their surgery. The participants' reflections of the surgeon's discussion about likelihood of blood loss during their planned surgery highlighted the role played by the surgeon in conveying this information. There were however differences in the participants' perceptions about the meaning of 'blood loss' from the surgeon's comments. Phrases such as "possible blood loss" or "high risk of blood loss as normal" were used to describe the participants' understanding of the information provided by the surgeon regarding potential loss of blood during surgery. No comments from participants indicated being given quantitative information about blood loss. For example participants did not recall being given information about the estimated amounts of blood loss that the surgeon anticipated for their type of surgery.

Studies show that predicting whether a transfusion will be required during elective surgery can be difficult. Larocque, Gilbert and Brien (1997) found the use of predictors including hemoglobin, weight and type of arthroplasty to be effective for predicting the likelihood of blood transfusion for hip and knee surgery. Within the province where the study was conducted, both the CBS and the facility protocols provide guidelines for health care providers with respect to patients' eligibility for autologous donation.

The CBS criteria indicate that there must be a reasonable likelihood of blood loss requiring transfusion with the elective surgical procedure in order for a patient to be accepted for preoperative autologous blood donation. Furthermore, the CBS criteria state, "only patients without serious medical illnesses should participate in this program" (CBS, Information Sheet, 1998). Protocols used to guide physicians in meeting patients' transfusion needs vary among facilities and across provinces. For example, the study facility has developed a protocol to be used as a guideline that identifies the most common elective surgical procedures for which either a type and screen or type and cross-match for blood be ordered. The protocol indicates a cross match for blood is not required for hip or knee arthroplasty, but indicates a cross match for two units of blood is recommended for a total hip revision. A hysterectomy is not indicated for either a group and screen or a cross match of blood. Protocols for head and neck procedures are dependent upon the type of procedure being undertaken. Spinal and liver surgeries are types of surgery for which there is a reasonable likelihood of blood loss requiring transfusion.

Changes to protocols to guide decisions for transfusion and the development of new techniques are reflected in certain types of orthopedic procedures. For certain orthopedic procedures, there are fewer transfusions administered than in the past due to the changes in protocols and new techniques used. Orthopedic surgery has been historically linked with high risk for hemorrhage (Keston & Enthoven, 1998). The change in practice may have contributed to the fact that there were no participants who underwent hip or knee arthroplasty in the study. The surgical procedures performed on the study participants included: spinal surgery (n=5), liver surgery (n=5), oral/neck (n=1) and hysterectomy (n=1). The liver and spinal surgical procedures were consistent with the guidelines for requiring a cross match for surgery to be done in anticipation of blood loss requiring transfusion. However, a hysterectomy does not, under normal circumstances, have a reasonable likelihood of blood loss requiring a transfusion. Another observation made was that the three patients undergoing liver surgery revealed their surgery was related to a growth or tumour. Two of the participants who had liver surgery reported that they had undergone major surgery within the past two years and were not approached about autologous blood donation. This raises the questions as to what is the appropriate intervention when patients request autologous donation when there is not a reasonable likelihood of blood loss requiring transfusion and how is the determination of "absence of serious medical illness" made for participants who wish to predonate?

A reasonable likelihood of blood loss requiring transfusion is one requirement of the Canadian Blood Services to be eligible for autologous blood donation.

Autologous Blood Donation and Other Options

Participants were asked a question regarding how they learned that autologous blood donation was an option for their consideration prior to having elective surgery. Participants learned that autologous blood donation was an option during a preoperative visit to the surgeon's office. Participants indicated that either the surgeon or the nurse in the surgeon's office, raised the issue of autologous blood donation in conjunction with the discussion of risk for blood loss in surgery. One participant stated it was a "question on a preadmission form that alerted her to the option of autologous blood donation". Another participant, a nurse, indicated she had first raised the issue of autologous blood donation, to the surgeon. The participants generally did not recall any other options such as blood salvage or hemodilution or alternative bloodless techniques being presented during the discussion of the risk of blood loss during surgery or during the discussion of autologous blood donation. The participants were prescribed adjunctive therapies including erythropoietin and iron preparations during the preoperative phase. The only memories participants had of hearing about other blood related techniques was just prior to surgery while in the hospital when either blood salvage or "saline" (hemodilution) were mentioned as potential interventions.

Summary

The researcher must first comment that the data provided overall by the participants was neither detailed nor specific regarding the first research question. From the participants' perspective, autologous blood donation was the only option presented by

the surgeon surrounding the discussion of blood loss during surgery. This was surprising to the researcher given that there has been a focus on ways to minimize the use of transfusions out of concerns for the transmission of blood-borne infections in recent years. Research about patients' experiences with autologous blood donation and other options is lacking. In the only Canadian study found regarding patients' experiences, Graham et al. (1999) conducted a comparison group study using a Likert scale questionnaire for patients undergoing elective cardiac and orthopedic surgery to assess patient perceptions and experiences with autologous and homologous blood. They found that 47% of the study sample learned about autologous blood donation from the surgeon and 38% from the media. Overall, participants in this study had some prior awareness of autologous blood donation, more from family experiences than through the media. Based on the data provided from the CBS, a small number of patients use autologous blood donation compared with the number of elective surgeries performed where there is a reasonable likelihood of blood loss.

For the majority of participants, it was the surgeon who raised the topic of autologous blood donation. This is consistent with the results of the Canadian study by Graham et al. that found 58% of autologous donor participants indicated "their surgeon suggested they predonate [autologous blood]" (1999). The participants did not investigate techniques prior to meeting with the surgeon which is in contrast to the literature that suggests that due to advances in communication technology, such as the internet and information sharing, patients have become more informed and more vocal regarding their expectations of health care (Moloney & Paul, 1993; Guadagnoli & Ward, 1998). The finding may have been influenced by the fact that 50% of the participants were greater

than 50 years of age and "embrace the authority and security" that includes for example, health professionals having control over decision-making (Moloney & Paul, 1993). Only one person in this study indicated having availed himself of information on the Internet.

The Second Research Question

Participants were asked a question about the factors used when making their decision to donate autologous blood. Three reasons identified as the main factors for predonation are discussed.

The Recommendation to Predonate

The most frequent factor mentioned by participants in response to the question regarding factors used to make a decision to predonate autologous blood was "because the surgeon recommended it". Comments made were not specific or detailed regarding the benefits or rationale provided by the surgeon in recommending autologous blood donation. Participants' perceptions of the reasons presented were that "healing factors were greater with autologous blood" and "recovery time would be better". The participants did not recall whether information about risks or side effects associated with either homologous or autologous blood transfusions was provided.

Reduced Risk For Homologous Transfusion

The participants did not have memories that reducing the risk of requiring a homologous transfusion and therefore reducing the risk of transmission of blood-borne

infections were rationale presented by the surgeon for using autologous blood. Neither did the participants recall any discussion regarding any inherent risk associated with autologous or homologous blood transfusions. Comments made by several participants reflected awareness that there is a risk for reactions to blood from their comments "it seems more logical to receive back my own blood. There wasn't going to be any reactions" and "it's certainly going to match better". The inherent risks in receiving homologous blood are well documented in the literature.

Safety of the Blood Supply

When participants were asked questions regarding the safety of the blood supply, participants' comments reflected wide variation in their level of concern. Three participants expressed a strong distrust in the health care system overall and took more initiative to gain control over their situation. One nurse participant requested and was accepted for autologous blood donation even though her type of surgery did not have a reasonable likelihood of blood loss requiring transfusion. A second nurse participant initiated discussion of autologous blood donation with her surgeon and raised the topic of what actions would be taken if the predonated blood were not a sufficient amount. Another participant conducted his own research using the Internet while he was enrolled in the autologous blood donation program to explore additional options and alternatives such as bloodless techniques. Another participant raised the issue with her surgeon as to what actions would be taken if the amount of predonated blood was insufficient. This participant had required blood in the past when a hemorrhage occurred and she indicated that she wanted to be prepared this time, but not "tie the surgeon's hands".

For the majority of the participants, although they expressed concern with blood safety in their statements including: "I was kind of leery", "I didn't want to receive other peoples' blood because of all *those* issues"; It did kind of bother me ...I was hoping that I didn't get some wild blood"; the participants did not indicate that any objections were raised or countermeasures taken to prevent receiving blood. These participants did not raise their concern to their surgeon or any other members of the healthcare team.

A possible reason for concerns about safety not being identified as a major factor in the participants' decision to donate autologous blood may be due in part to the study design. Participants were interviewed during their postoperative phase after the autologous blood donation process was complete. Participants stated they were satisfied with both the amounts and types of written and verbal information provided about autologous blood donation from the CBS when they went to predonate. Comments were made that indicated nurses at the Canadian Blood Services provided information about changes to the blood supply to make it safer and minimize the risks for transmission of blood-borne infections. Any concerns that the participants may have had about blood safety may have been allayed by this information coupled with the fact that they were also reducing the risks by donating their own blood.

Summary

A review of the literature demonstrated that autologous donation is a safe and effective treatment for selective preoperative patients to reduce the risk of transfusion reaction and exposure to transfusion-transmitted diseases (American Expert Panel, JAMA, 1990). There is a lack of Canadian published research of surgical patients' perceptions and experiences with autologous blood donation. The main reasons expressed

by participants for choosing autologous blood donation, being the recommendation by the surgeon and personal concerns about the safety of blood, were consistent with the main reasons identified by Graham et al. (1999). Graham et al.'s (1999) study into patients' perceptions and experiences with autologous blood donation found "avoiding infection with HIV, hepatitis virus or other blood-borne pathogens, simply feeling safer and having a rare blood type" in descending order were the reasons given for predonating autologous blood. The fact that the majority of the participants were greater than 50 years of age may have influenced their decision to accept the recommendation of the surgeon. Moloney and Paul's (1993) published works report that the past generation, having suffered through wars and a major depression, embraced authority and security. They indicate that past generation patients hold physicians in high respect, look to the doctor for advice and follow it. The participants who took the most initiative in seeking the autologous blood donation option were younger and were nurses. These attributes reflect the shift in expectations and preferences of the health care system that have occurred with the coming of age of the baby boomers. The research shows that in sharp contrast to the past generation, the vounger generation seeks far more involvement in decision-making (Guadagnoli & Ward, 1998).

The Third Research Question

The study participants were asked to describe their expectations with respect to the autologous blood donation experience. The participants had difficulty in identifying or describing in detail their expectations. This may have been a result of the study design.

The interviews were conducted during the postoperative phase in accordance with the approved study protocol. Since the patients were not interviewed prior to or during the autologous blood donations, their perspectives and expectations regarding the autologous blood donation experience are retrospective reflections and may have changed over the course of the experience.

None of the participants had any prior personal experience with autologous blood donation. The majority of the participants had no experience with receiving blood transfusions and were not recent blood donors. Two participants had recently had major (general) surgery and had not been offered the autologous blood donation option. The researcher interpreted their comments as indicating that the participants expect options to be presented or to be informed if an option is not a suitable one.

The participants did describe in detail many variables with respect the blood donation appointments and indicated satisfaction with information provided as will be presented to follow. Participants were also asked questions as cues to identify other possible areas of information provided that were not described in the participants' recollections.

Blood Donation Appointments

The researcher's belief was that the participants' expectations of services provided would be reflected by their expressions of "satisfaction" with the various components of the autologous donation experience. Patient satisfaction surveys are being used with greater frequency as one mechanism to measure patient's perception of their experience as well as outcomes of the care received (Shortell et al., 1995). Survey

instruments most frequently include indicators such as explanations, whether given and type of information, technical skills, and ambiance of the facility (Acorn & Barnett, (1999). The participants' comments and reflections in describing their expectations of the autologous blood experience were consistent with the indicators of patient satisfaction found in the patient satisfaction literature. Participants' comments included details surrounding appointments including accessibility, ambiance, convenience, length of time and screening process. Other aspects of the blood donation experience and expectations that were highlighted included: manner of treatment by staff, information provided and safety interventions during the blood donation procedure itself.

Accessibility

None of the participants had difficulty with accessibility to a blood services centre to predonate their autologous blood. Participants either resided in the city where the CBS Centre was located or resided close to the rural satellite Centre. There are only two Centres where autologous blood donations can be made preoperatively in the province where the study was conducted. Participants indicated that travel or other personal costs incurred when donating their blood were not an issue. This was different from the findings in a study conducted by Graham et el. (1999), in which distance traveled to access a blood donor center and related travel costs were raised by participants as disadvantages to ABD.

Ambiance

Participants' recollections about the appointments at the urban Centre were positive for ambiance as indicated in their comments: "an impressive center", "convenient...parking", and "beautiful". The CBS Centre is less than two years old and it is therefore not surprising that the participants would comment positively on the building.

Convenience

The participants did not raise convenience of appointments as an issue. The researcher assumes that convenience of appointments was not raised as an issue because the participants had access to the centers. Furthermore, the majority of the study participants received erythropoietin injections twice weekly. While questions were not asked about this treatment, no participants raised the number of appointments that were required to receive treatments or donate blood, as an issue. In addition, the majority of participants were on a leave of absence due to illness or retired and therefore scheduling appointments was likely not an inconvenience.

Length of time and screening process

Participants indicated that the length of time for appointments was "not a problem" with the exception of the screening process. There were different opinions about the screening process that was undertaken prior to the donation. Several participants commented that the screening process was "very thorough" and "lots of duplication, to make sure that *things* weren't getting mixed up". They saw the screening as an example of making the system a "safer" one. These participants saw the thorough

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screening as an example of changes to the system to make the occurrence of "errors less likely". Others indicated it "took a long time" and "the screening was long, considering you are getting your own blood". They commented that they found the questions in the screening process to be "quite personal" when " the blood is coming back to you" and "unused blood is thrown away".

Manner of treatment by staff

In describing the predonation experience participants also spoke of the manner in which staff, nurses and others treated them, during the procedure. The majority of participants used words and phrases in their recollections that portrayed staff as "friendly" and "helpful". Three participants made negative comments about specific problems encountered during the venipuncture procedure and a concern that the blood typing was incorrect. The negative comments centered on skill sets and or competency rather then specific attributes of the provider. It is important for care providers to gather data from patient's experiences, both negative and positive. According to Gerteis et al. (1993), experts in patient satisfaction, it is not only the experience but also what the patient thinks about the experience that will determine how patients use the health care system.

Information about Autologous Blood Donation

Participants generally indicated that written and verbal information was provided and the information was "sufficient". Any written material provided was not available during the interview process for the researcher to examine. The nurses played the major

role in providing the information during the donation of blood. The participants' recollections focused mainly on describing the autologous blood donation, i.e. the number of times they could donate prior to surgery, the screening process and the blood donation intervention. The CBS publishes a pamphlet and other written material and has a web site with information about the services they provide, including the organization's annual report and other specific information such as transfusion and autologous blood donation processes. There is a patient information document available to physicians to give to patients when discussing the autologous blood donation option with patients (Appendix A). It was not clear from the patients' comments whether they had received a copy of this information.

Several participants recalled that there was an emphasis on the safety of the blood supply, but they could not recall information about the risks associated with transfusions, autologous or homologous, being provided. Recollections of participants were that the risk of infection with receiving transfusions of blood from others "was minimal". The risk for transmission of HIV and other viruses is included in a patient information pamphlet that is available through the study facility. For example the risk for HIV infection is reported as 1 in 900,000 (Facility Pamphlet, 1998).

Information Not Recalled

There were three areas for which participants could not recall information being provided or were unable to be very specific about the information or discussions held surrounding these areas. The areas included: side effects or risks associated with

autologous blood transfusions, actions to be taken in the event the predonated autologous blood does not meet requirements, and unused predonated autologous blood.

Information of Side Effects

Participants had difficulty recalling any specific information about risks or side effects associated with autologous blood transfusion. The participants' comments focused on advantages of their own blood being a "better match" and reduced risk for blood-borne infections. These advantages are consistent with those cited in the literature (Stowell et el., 1993). Additional advantages of autologous blood donation reported in the literature are reduced length of hospital stay and risk of complications (Farrer et al., 1997). Farrer et al. (1997) found the risk of postoperative complications such as inflammatory response or sepsis was reduced by more than 50% and the length of stay reduced by a mean of 3 days in patients who used ABD prior to undergoing abdominal aortic aneurysm repair.

The potential for clerical error remains a risk with any type of transfusion intervention. Errors can occur in labeling, shipping, or uninformed care providers (Goldman et al., 1997). The majority of participants in this study did not comment on the potential for clerical error. The participants who did raise concerns about the potential for clerical errors had some connection with the health care system. Two were nurses, one was a health care clerical worker and one had a daughter who was a nurse. Their background may have influenced their raised awareness for clerical error. One of the nurse participants commented that she felt the proper labeling had not occurred on her identification band that could potentially lead to an error.

Unused predonated autologous blood

Participants' comments for example "they throw it away?" and "they only use the plasma" indicated that participants either could not recall what happens to the blood or had an incorrect perception. The CBS policy is that any unused autologous blood is discarded (E. Giesbrecht, personal communication, CBS, 1999). The CBS patient information document does describe the testing done to the donor's blood, for example, blood grouping and typing, presence of antibodies, and evidence of infection. The document states that the "pre-transfusion tests are performed even though the patient will be receiving back" his or her own blood to reduce the risks to the patient.

Two participants raised the issue of the cost-effectiveness of discarding unused portions of autologous blood, when the screening procedures are the same as for homologous blood. Several participants commented that they assumed that the blood or components of their blood could be used for other purposes. No studies were found that focused on this issue. The cost-effectiveness of autologous blood when compared to homologous blood transfusion has been examined in ABD studies. Because there are significant differences among health care systems with respect to costs borne directly by the patients for services provided, it is important to use Canadian research. The Canadian Health Care System, of which the Canadian Blood Services is an integral part, is a publicly funded and administered system with universal access to services. It was the researcher's belief that because patients are not required to pay directly for health services, the participants would not be as conscious of the associated costs. It was a nurse participant, who may have been more conscious of health care costs, who raised the cost-effectiveness of discarding any unused blood as an issue.

Only one Canadian study was found in the review of the literature regarding costs associated with autologous transfusion collection, production, distribution and delivery. In the Canadian study conducted into transfusion costs, Tretiak et al. (1997) reported the mean cost per unit of autologous blood was significantly greater than that of homologous blood. Cost-effectiveness of autologous blood donation and other alternatives to transfusions was not considered in this study.

Personal costs associated with autologous blood donation

None of the participants identified personal costs, for example, travel to appointments as an issue. A limitation of this study was that the sample inclusion criteria required the participants to reside in the urban areas where the blood donation center was located.

When predonated blood does not meet transfusion needs

The participants' comments varied a great deal with respect to information provided or discussion that occurred surrounding the possibility of requiring blood greater than the amount predonated.

None of the participants indicated they would not accept homologous blood if the physician was faced with a circumstance requiring it. While some participants recalled a very specific conversation reaching an agreement that blood from others would be administered only as a last resort, others did not recall any discussion. It was the perspective of several participants that a consent form had been signed agreeing to accept

the blood of others. The participants' reflections do raise an important issue of informed consent. In his report Krever (1995) acknowledges that providing information about the risks of transfusion and asking patients to sign consent for blood or blood products has not been the past practice of health care professionals. The expectations of patients in the modern health care system is that they be more informed and have more control over decisions surrounding their care (Feste & Anderson, 1995; Guadagnoli & Ward, 1998; Krever, 1995). It was surprising to the researcher that this issue had not been raised prior to surgery.

Hemodilution and blood salvage are other alternatives or adjunctive therapies to homologous blood transfusion. Several study participants had some recollection of these options being presented and at least one participant indicated that blood salvage was used. Decision-making is a complex process. Inherent in the definition of decision-making is that options are presented.

While the purpose of this study did not examine the patient's decision making process itself, it is the researcher's belief that the factors used to make a decision to donate autologous blood are influenced by the amount of information provided about other options.

Summary

The participants did not have previous personal experience with autologous blood donation. For the purposes of this study, participants were not interviewed prior to surgery; therefore the study did not explore any differences between preoperative and postoperative expectations. Participants did not verbalize specific expectations for the

autologous blood donation experience. They did however raise common themes in their reflections surrounding the autologous experience including the convenience of appointment, the information provided, manner of treatment and information provided. The themes that emerged are consistent indicators of a quality service in the patient satisfaction literature. There were aspects of information that participants could not recall receiving that may affect their expectations about autologous donation. These areas included: side effects associated with autologous blood donation and transfusion, interventions to be used when autologous blood is not sufficient to meet the patients' needs and the policy of discarding any unused autologous blood.

The Fourth Research Question

The study participants were asked a question about the actions they would take regarding autologous blood transfusion if surgery were required in the future. The findings are first discussed in relation to the outcomes of the donated autologous blood followed by the discussion of the actions the participants would take in the future.

Autologous Blood Donation Outcomes

The participants indicated they would definitely use or recommend autologous blood donation to others in the future. Two participants also indicated that they would now like to become regular blood donors if their health would permit it. The CBS literature does include information that a positive outcome for the organization with autologous blood donation is that autologous donors often become regular blood donors contributing to the overall blood supply. Their comments however did not identify

concrete reasons why they were so positive about using it again. For example the participants did not comment that the accessibility and convenience of donating autologous blood or that homologous blood was not required were the main reasons for their strong recommendation.

In examining why the participants were so positive about the autologous blood donation experience, the researcher looked to comments made about the blood donation itself, and about the experiences with blood or other alternatives used during the hospitalization. In particular, convenience with appointments, lack of side effects with donation or transfusion, and the fact that homologous blood was not used are considered.

Convenience

The participants' strong recommendation for autologous blood donation may have been influenced by the fact that they had no difficulty accessing the program and found the appointments to be convenient. This assertion is consistent with Graham et al's (1999) study of patient's perceptions of the autologous blood donation experience. Their study results showed that participants' reasons for not considering autologous donation in the future were related to the appointments being "too inconvenient", "too much trouble" and "too time consuming".

Reduced risk of blood borne infections

From the patients' perspective, no homologous blood was administered. The researcher did not have access to the patients' records to verify whether the patients' perceptions were true. The study participants indicated that the risk of receiving blood

from others and the transmission of blood borne infections were concerns. By recommending autologous blood donation, the physician provided an option that reduced both the risk of receiving homologous blood and a blood-borne infection. Participants' positive response to the autologous blood donation may reflect the positive outcome of not having received any homologous blood. What cannot be answered in this study is whether the participants would choose autologous blood donation in the future if they had received homologous blood.

The majority of participants were receiving erythropoietin injections and an iron preparation during the four-week interval that autologous blood was being donated. Four of seven patients receiving these adjunct therapies were transfused with the predonated autologous blood. Further research is needed to determine the cost effectiveness of autologous blood donation when combined with other therapies.

Reactions or side effects experienced during ABD

Another reason for the participants' positive recommendation for future autologous blood donation could lie with the fact that the majority of participants reported no side effects or reactions during the autologous blood donations. Two participants reported dissatisfaction during one autologous donation that they attributed to the skill set of the person doing the venipuncture. One participant indicated that bruising had occurred at the venipuncture site. Another participant indicated that the first blood donation was terminated before completion due to the needle being incorrectly placed.

Two possible side effects associated with autologous blood donation identified by The American Panel of Experts (JAMA, 1999) are vasovagal reactions and

delayed surgery. Vasovagal reactions occur in about 2% to 5% of all blood donors, autologous or homologous (JAMA, 1990). The symptoms of a vasovagal reaction include hypotension and bradycardia that result in feeling "lightheaded". The patients in the Canadian Health Care System do not determine specific dates for surgery. However there may be changes to the scheduled date of surgery in certain circumstances for example emergency situations that require the services of the surgeon or the operating room theatre. There were no significant delays in the planned surgical dates of the study participants. There are implications for costs associated with autologous blood when elective surgery is cancelled. The expiry date for autologous blood is 35 days. When the date for surgery is changed, one or more predonated units of blood may expire and must be discarded. Furthermore, there may not be an opportunity to predonate the planned number of units, in which case, the patient's needs to address anticipated blood loss may not be met. The participants in this study generally indicated that they had predonated the number of units recommended by the physician. Experiencing no pain or slight pain by the majority of participants undergoing autologous donation was consistent with the findings of Graham et al. (1999). They found 83% of patients undergoing donation did not "feel bothered" by side effects of autologous donation and 78% reported no pain. Two participants in this study each indicated one experience where they had experienced pain during the donation.

Reactions or side effects with autologous blood transfusion

Of the 28 autologous units predonated, 13 units were administered to seven of the 12 study participants. The majority of participants were transfused with their blood while

in the operating room or recovery room and had no recollections of being transfused with blood as reflected in the comments of one participant who stated, "They told me I had received them [the 2 units of autologous blood] both". The participants also indicated that no one had indicated to them that there were any difficulties with administering the blood. Two participants received autologous blood transfusions during the postoperative phase. Both participants indicated they were not aware of any reactions. One participant commented on the precautions the two nurses took in checking and "double checking everything" during the administration of her blood.

Future Considerations

Study participants' reflections gave rise to two issues that are important for future research: the practice of discarding unused predonated blood and the policies in place for directed donation.

As mentioned in a prior section of the study, participants commented that they did not know that autologous blood must be discarded. The question was raised as to whether this was cost efficient if the screening process is the same as for donating blood for the general supply.

The issue of directed donations was not examined in this study. However, several participants did raise this as an issue.

Summary

The autologous blood donation experience was positive as reflected in the participants' comments that they would definitely recommend autologous donation to others and /or donate again themselves in future if surgery were required.

The researcher attributed the positive experience to the lack of negative comments with respect to the autologous blood donation outcomes: that the autologous program was accessible and convenient, that homologous blood was not used, and there was a significant number of side effects or reactions with either autologous blood donation or autologous blood transfusion.

The indicators of quality care in satisfaction studies are consistent with the aspects identified by participants for a positive autologous blood donation experience. The findings do identify that information needs are not adequately met with respect to two issues. The first is action to be taken when additional blood is required beyond the autologous blood donated and the second is the policy that requires any unused donated blood to be discarded. Participants would like to see expanded polices for directed donations.

Relationship Of The Findings To The Conceptual Framework

Becker's (1974) Health Belief Model (HBM) provided the conceptual framework for developing the semi-structured interview guide used to gather data about the perspectives and experiences of pre-operative patients with autologous blood predonation. The three major components in Becker's (1974) framework are: individual perceptions, modifying factors, and the likelihood of taking action (Appendix B). This

model advocates that in order for individuals to avoid a disease, in this case a bloodborne infection, they would need to believe (Becker, 1974, p. 3):

- i) that they are susceptible
- ii) that the occurrence of the disease would have at least moderate seriousness on some component of their life
- iii) that taking a particular action would be beneficial

Individual Perceptions

The participants in this study underwent major (elective) surgery and were faced with a reasonable likelihood of blood loss requiring transfusion. Individual perceptions in this study included the perceived severity of blood loss during surgery requiring transfusion and perceived susceptibility to acquiring a blood-borne infection through a transfusion. According to Becker (1974), the acceptance of one's perceived susceptibility to a disease and beliefs held about its seriousness provide the "energy or force" for action (p. 5). The likelihood of action is influenced by an individual's beliefs about the availability and effectiveness of known alternatives in reducing the threat, which in this case refers to reducing the risk of homologous transfusion.

However, according to Becker's (1974) model, the combined levels of susceptibility and severity, and perception of benefits may not result in an individual taking overt action. Two groups of modifying factors influence the likelihood of taking overt action. First are factors including: demographic variables, sociopsychological variables and knowledge or structural variables that influence the individual's perception of susceptibility and seriousness of a disease. The second are factors that provide 'cues to

action' (for example the mass media coverage of the tainted blood scandal). The HBM components were used to develop the semi-structured questionnaire in order to gather demographic data and qualitative data about the participants' perceptions, knowledge, and experience with autologous blood donation.

Modifying Factors

The study findings for demographic data, structural variables and cues to action are presented in relation to Becker's (1974) Health Belief Model.

Demographic Variables

The demographic data collected for this study included: gender, age range, level of education, work type, employment status, type of surgery, and blood transfusion and donation history. Sociopsychological data, for example, personality, social class, peer and reference groups, were not collected for the purposes of this study. In the Canadian Health Care System, of which the Blood Supply is a part, health care is publicly funded and access is universal. Therefore, the researcher did not deem sociopsychological factors other than years of education to be applicable for this study design.

The examination of the relationship of the findings for age, work type and type of surgery, were congruent with the HBM. The study participants fell into the 18 to 69 age categories. The participants who were greater than 50 years of age expressed a greater degree of trust in their physician's judgment and perceived the risks as less serious. Some participants in the under 50 years age range, and in particular those who were employed within in the health care system, were less trusting of the blood supply system and felt

more threatened. The greater the perceived threat the more motivated the participant is to take action. This is illustrated by one study participant who was a wife and mother, was educated (nurse) and who faced a major surgical procedure to remove a tumour from an areas that could cause a fatal hemorrhage during dissection. The participant also expressed fear and paranoia about blood safety. It was this participant's belief about the safety of blood, her vulnerability with the severity of her illness, and her perceptions that this was a beneficial option that prompted her to initiate the ABD process with her surgeon.

The types of surgery being performed influenced also how the patients viewed their vulnerability with respect to the anticipated blood loss. The study sample (n=12) was comprised mainly of patients undergoing either spinal or liver surgery. Patients who were undergoing liver surgery related to cancer or possible cancer viewed autologous blood donation as an opportunity to take some control, as beneficial to avoiding another potential health problem. Their perceived vulnerability influenced how they viewed their susceptibility, which is congruent with the Health Belief Model.

The study group was comprised of an equal number of women and men. The findings did not reveal any differences for gender as a modifying factor in influencing the action taken to donate autologous blood. This may be due to a limitation of the sample size and selection process and not attributable to the model.

Structural Variables

Knowledge is a structural variable identified as a modifying factor in Becker's (1974) HBM. None of the participants in this study had any prior experience with

autologous blood donation. Except for the two nurse participants, it was the surgeon who first raised the discussion of loss of blood during surgery and the option of donating blood. At the time the ABD option was presented to the participants by their surgeon, none of the participants had knowledge about autologous blood donation except awareness. The participants commented that their awareness about autologous blood donation stemmed from family members and others who donated blood, from media coverage of the Krever Commission of Inquiry into the tainted blood scandal, as employees in health care and because they had heard about it 'somewhere'. The participant's awareness of ABD, through family, media, and occupation were not factors that served as cues to take the action of initiating autologous blood donation when faced with surgery.

Assessment of the level of knowledge regarding the transmission of blood-borne infections was not conducted in this study. However, participants were asked if donating autologous blood was motivated by concerns over the safety of the blood supply and or risks with acquiring a viral infection with a homologous transfusion. Participants' comments indicated they had concerns, but they, with the exception of one nurse participant, did not voice these concerns to the surgeon or any other health care provider at the time autologous blood donation was raised. The participants' may have had their concerns allayed during the donation process when more detailed information was provided to them about the safety of the blood supply and about autologous blood donation benefits.

Cues to Action

Cues for action are factors identified in the HBM as events, either internal (i.e. perception of bodily states) or external (i.e. impact of media) that are sufficient to trigger action or a change in behaviour (Becker, 1974). The participants did not mention media coverage of the concerns of the safety of the blood supply or the Krever Commission of Inquiry as the main factor in their decision making process. Therefore the researcher made the assumption that this was not a cue for action to donate autologous blood. Recently, there has been a focus in the media on the changes that have made the blood supply system safer. It is not clear what role the positive coverage of the safety of the blood supply system had on the participants' perception of their susceptibility to risk of transmission of blood-borne infections. According to Becker, identifying the role of cues retrospectively is very difficult to measure.

However, the majority of participants did identify that it was the recommendation of the surgeon that was the major factor in their decision to accept ABD. Advice from others, in this case the surgeon, is a cue for action identified in the HBM (Appendix B). The participants' acceptance of the recommendation from the surgeon, without knowledge of other alternatives, indicates a trust of the physician's judgment and a perception that donating blood was seen as beneficial and safe.

The participants' acceptance of the surgeon's recommendation of autologous donation in combination with the lack of barriers to donating autologous blood provided the likelihood that ABD would be chosen. The lack of barriers such as access to the blood donation center, convenience of appointments, manner of treatment, and no undue personal expense were seen as benefits for choosing ABD. Most of the participants also

indicated there was no discomfort with donating. Two participants had each had one experience where the venipuncture either caused bruising or was very painful.

The trust in the surgeon's judgment regarding the amount of blood to donate preoperatively may have influenced the participants' perception that no other blood would be required and therefore no discussion was needed surrounding the issue. This was demonstrated by the fact that the majority of the participants did not raise this as a topic for discussion. There were two participants, who work in health care, who indicated that they raised the issue with their surgeon. All of the participants indicated they would accept homologous blood if it were required during the surgery.

Summary

In summary the Becker's (1974) HBM provided a flexible conceptual framework to study the autologous blood experience for elective surgery patients. The HBM is an appropriate model to explore perceptions and experiences and to identify and describe factors used to donate autologous blood. The HBM would be useful in designing future studies to gain further insight into patients' expectations and experiences with autologous blood donation.

Recommendations

Practice Implications

This study has several implications for the nursing profession and other stakeholders in the provision of care to patients. While the surgeon plays a key role in providing the elective surgical patients with information about the blood loss and likelihood of requiring transfusion and identifying a variety of options to deal with the blood loss, the nurse also plays a critical role in coordinating, educating, treating and administering to the patients surrounding the autologous blood donation experience.

Nurse practitioners in the surgeons' office have the unique opportunity and scope of practice to work collaboratively with the surgeon in identifying the needs and expectations about blood and blood use from the patient undergoing surgery. Nurses in preadmission clinics have a responsibility to assist the patient with meeting their information needs in relation to the surgical experience, specifically blood administration and how safety is addressed in administration of blood if required. Nurses in the blood donor clinics have the two fold responsibility of ensuring the patients' information needs and that the autologous blood donation experience is a safe and satisfactory one for them.

Nurses providing the preoperative, operative and postoperative care of the patient have a shared responsibility for ensuring the information and safety needs are met in the administration of blood and blood components during the perioperative experience.

Imperative throughout the autologous blood donation experience is the need for all involved care providers and stakeholders responsible for setting public policy to be

attentive to the needs and expectations from the perspective of the patient to allow the patient to make choices based on the correct information and the correct perceptions.

Implications for Nursing Education

Findings of this study have implication for nursing education. Nurses and nursing students need to be educated about the critical role they play several aspects of the blood supply processes. Nurses are well positioned to gather information about the needs and expectations of patients who are faced with difficult choices about blood transfusions. Nurses also play a critical role in providing for the safe administration of blood in hospitals and donor clinics due to the fact that a large number of the hospital policies and procedures related to the administration of blood pertain to the practice of nursing.

To enhance the education of nurses, it is important to publish the results of this study and to present the findings to health care providers so that changes to practice and education are made based on evidence from research.

Suggestions for Further Research

There is a lack of published nursing research into the surgical patients' perspectives and experiences with autologous blood donation. To plan appropriate intervention programs there is a need for further research to determine patients' needs and evaluation research to determine the effectiveness of the program in meeting a need.

Suggestions for further research regarding patient perspectives were identified from the study findings:

- i) The sample in this study was small and limited in the variety of the types of surgery performed. Using a larger sample and a sample representative of other types of surgery especially orthopedic surgery, with varying accessibility to programs and from different areas of the country would allow the findings to be generalized. Expectations of patients with past experience with autologous donation may be different from patients without experience and a study design would need to address this difference.
- ii) The expectations of the patients in this study were examined retrospectively only. To gain a better understanding of expectations measures should be conducted both pre-operatively and post-operatively.
- This study did not examine the effects of autologous blood donation on recovery time. Adjunctive therapies were used in this study. Research could be done to examine the effectiveness of these interventions when used with autologous blood donation.
- iv) The participants' perspectives of ability to resume a normal activity of daily living when compared to non-donors.
- v) The participants' awareness of inherent risks with both autologous and homologous blood transfusions
- vi) The mechanisms by which the public can be made aware of all available options, including risks, costs and benefits to assist with decision making surrounding blood loss during elective surgery.

vii) The cost-effectiveness of autologous blood donation when used in conjunction with other therapies such as erythropoietin.

Conclusion

This descriptive study has gained insight into the experience of the surgical patient with autologous blood donation. There is a lack of research into this topic with only one Canadian study found (Graham et al. 1999) that examined autologous blood donation form the patients' perspectives.

A qualitative method is appropriate to look at experiences through the patients' eyes. The findings demonstrate that for this sample, autologous blood donation was a positive experience. No homologous blood was transfused; therefore the study participants experienced a reduced risk of acquiring a blood borne infection. Both physicians and nurses play critical roles in ensuring the public is fully aware of all options and alternatives when faced with a decision that will require the administration of blood or blood products.

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Appendix A

Canadian Blood Services, Autologous Blood Donation Program Patient Information (modified to maintain confidentiality of study setting)

1. WHAT IS AN AUTOLOGOUS BLOOD DONATION?

The Term "autologous donation" refers to the collection of blood from a person to whom it may be transfused at a later time.

2. WHO IS ELIGIBLE TO DONATE AUTOLOGOUS BLOOD?

Persons for whom elective surgery is planned may be eligible to donate autologous blood if there is a

reasonable likelihood that transfusion will be needed, and if the person is in good health.

3. WHAT NEEDS TO BE DONE?

a) Your doctor must send a request to Canadian Blood Services. The name of the form your doctor must send in is *Physician Request for Consideration for Autologous Transfusion*.

This form includes:

- details about your surgery and your general health
- how many units your doctor would like you to donate prior to your surgery. The minimum number is 2, and the maximum number of units is 4. All of the units must be collected in the 35 day period immediately prior to your surgery date because whole blood can only be stored for 35 days.
- your hemoglobin (blood count) level. Your doctor may suggest that you take iron supplements during the donation period to maintain your hemoglobin level as high as possible.
- b) Canadian Blood Services Centre will contact you to schedule appointments for your donations.
- c) Autologous donation appointments will be made for one of their sites.

4. HOW MUCH BLOOD DO YOU TAKE?

Each donation (unit) is approximately 450 ml of blood. This is about 10% of your total blood volume. Donations are generally made at 1 week intervals.

5. <u>CAN I SAFELY DONATE SEVERAL UNITS OF BLOOD IN SUCH A SHORT TIME?</u>

Yes. The liquid portion of the blood (plasma) is replaced by your body in 24-48 hours after a donation. It takes 6-7 weeks for your body to replace the red cells. This is why your doctor may recommend iron.

If you start with a normal hemoglobin level and take iron supplements, blood donations may be made as often as once a week without producing a serious degree of anemia. You may develop mild anemia, but this is unlikely to interfere with your surgery.

Generally between two and four units of blood may be collected safely before surgery. Your hemoglobin level is checked before each donation to ensure that it is safe for you to make another donation. If you feel unwell, light-headed or dizzy during the weeks you are donating, please contact your doctor.

6. WHAT IS DONE WITH THE BLOOD I DONATE?

Your blood is collected into blood bags containing a solution which prevents it from clotting and also keeps the red cells alive during the storage period. Each of your units of blood is labeled so that it will used only for you. Your blood is kept in a special refrigerator at a temperature of 4^{0} C.

Each unit of your blood undergoes all the regular Canadian Blood Services tests including test for hepatitis B and C, syphilis, HIV (antigen and antibody test) and HTLV-I/II (human T-Lymphotropic virus).

Even though you will be receiving your own blood, the tests listed above are performed. If a possible infection is identified which would carry risks for those handling or transfusing your blood, further autologous blood donation may not be permitted. If any positive test results are identified, both you and your doctor will be notified. Positive test results will also be reported to the Department of Health if required by the law.

Your units of blood are stored in the Canadian Blood Services Centre blood bank and are supplied to the hospital at the time of your surgery as requested by the hospital. The units are designated for your transfusion only and, prior to transfusion, each unit will be crossmatched with a sample of our blood to ensure compatibility.

Appendix B

Becker, M. (1974). The Health Belief Model and Personal Health Behavior.

New Jersey, Charles B. Slack, Inc. p.7

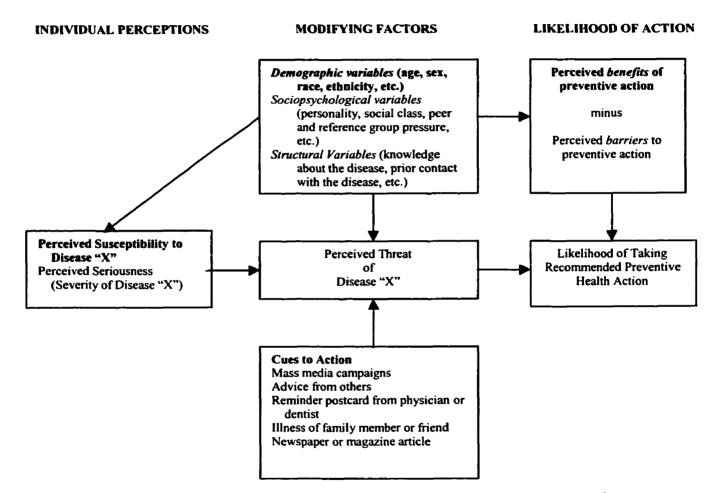


Figure 1 The "health Belief Model" as predictor of preventive health behavior (after Becker et al. 9).

Appendix C

Invitation to Participate in a Research Study

My name is Betty Frost and I am a student in the Master's of Nursing Program. I am doing a research project on the topic Autologous Blood Donation as part of the Master's program. I am very interested in gaining an understanding into what types of factors you used to make your decision to participate in the autologous blood donation program; in learning about whether the autologous blood program met your expectations and needs; and what decision you would make if you had to have surgery again in the future.

Your participation in the study would be helpful to health care professionals to gain insight into the factors you used to make your decision to donate autologous and what your experience was with autologous blood donation overall.

You are invited to participate in this research project if you meet the following criteria:

- 1. have donated at least one unit of blood through the Blood Centre prior to having your surgery
- 2. are 18 years of age or older
- 3. are able to speak and understand English
- 4. have a telephone
- 5. reside in designated city or the surrounding area

Your participation in this research project will involve a 1 to 1 1/4 hour interview. In the interview you can describe in detail to me your experience with autologous blood donation. The time and place of the interview will be at your convenience. The interview will be audiotape recorded, then transcribed and analyzed. The results of the analysis will be available to you. All information collected will be kept confidential and you will remain anonymous in accordance with the Privacy of Health Information Act (PHIA). Your participation is voluntary.

If you are interested, or have any questions please keep the tear off portion and call me at the number listed below

Betty Frost

Phone

Appendix D

Interview Guide

- 1.Please describe for me any past experiences you have had with blood transfusions or with donating blood, not including this pre-operative blood donation experience.
- 2. Once you learned that you needed to have surgery, what information and who were the sources of information about the possibility of requiring a blood transfusion?
- 3. What can you recall about the information or explanations that you were given about the topic of blood loss and options surrounding this in relation to your surgery?
- 4. What type of communication did you receive about any aspects of your surgery (eg written, verbal, video)
- 5. What types of information (factors) did you use to make a decision about blood options and the decision to make an autologous donation?
- 6. Please describe as fully as you can recall the experience with making the autologous blood donation (s).
- 7. What happened to your blood?
- 8. What were your expectations of the pre-operative donation of blood program? How were your expectations met, not met or exceeded?
- 9. What would you do differently about blood options if you were required to have surgery again in the future?
- 10. Is there anything that you have not covered that you would like to discuss? Has the discussion been of value for you?

I have some other questions that I would like to ask about your background:

What type of surgery did you have?

Gender M F

What is your age category: 18-29 years

30-39

40-49

50-59

60-69

>70

Are you employed?

What type of work do you do?