UNIVERSITY OF CALGARY

Learning and Resource Needs and Capacities Assessment of Rural Hemophilia Health Care Providers

by

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled "Learning and Resource Needs and Capacities Assessment of Rural Hemophilia Health Care Providers" submitted by Andrea M. Pritchard in partial fulfillment of the requirements for the degree of Master of Nursing.

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ABSTRACT

This study explored resource needs and capacities of rural health providers as foundational to understanding partnerships between urban and rural professionals and families. As hemophilia care is coordinated through urban services, the question arose if rural health professionals believed they had adequate preparation for safe and effective hemophilia care. Participants included nurses, physicians, social workers, physiotherapists, pharmacists and lab technologists from 11 southern Alberta and southeastern British Columbia communities with a residing hemophiliac. The study proceeded in three phases: focus group interviews (11 participants), telephone interviews (9 participants), and mail-out survey (56 participants). Analysis of focus group and telephone interviews vielded five categorical themes: objective knowledge, subjective knowledge, communication, team roles and partnerships. Themes were used to develop survey questions. Identified resources compared against availability revealed significant needs. An education day was implemented based on needs; evaluation demonstrated an overall increase in readiness to provide safe and effective care.

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EPIGRAPH

You need to help lots of people out. But first you have to know

what I am about... and what they are about...and what you are about...

before you can really do anything good.

That's the something you need to figure out.

11-year old boy with hemophilia on his nurse's research project (2002).

CHAPTER ONE

STUDY OVERVIEW

Introduction

About three thousand Canadians living with hemophilia are supported by 1 of 23 regional multidisciplinary comprehensive care programs. However, not all families with hemophilia live in the urban centre where such specialty programs exist. The urgent nature of hemophilic bleeding coupled with the relative rarity of this disorder presents an obvious challenge in the preparation of health care providers who practice in rural and remote communities. Furthermore, an additional challenge exists in that multidisciplinary rural hemophilia health care providers experience compounding demands related to their own geographic isolation from specialty clinic supports. Given the nature of hemophilia and rural care, this study was designed to explore the learning and resource needs and capacities of rural hemophilia health care providers. It was based on the belief that the providers' perspective is foundational to effective and sustainable preparation for hemophilia rural health care delivery.

Study Purpose

Research-based evidence on learning needs and capacities unique to hemophilia rural health care delivery has not been located in the literature. Therefore, a systematic exploration of such needs and capacities was required to develop evidence-based resources and educational programs specific to rural hemophilia health care providers. This identification is a cornerstone

requirement in the preparation of rural health providers for safe and effective hemophilia care delivery.

Background

Across Canada, comprehensive care services are provided by multidisciplinary, hospital-based teams within 23 Hemophilia Treatment Centres. The Calgary Health Region Hemophilia Clinic serves 103 people with hemophilia living in southern Alberta and southeastern British Columbia. Within this large geographic area, 28 people with hemophilia live in 11 rural communities. These individuals require the support of routine, urgent and emergency health services within their rural setting. As hemophilic bleeding and disease-related complications are not predictable, associated requirements of health care providers are similarly challenging. Even so, a systematic examination of learning and resource needs and capacities, identifying what rural health providers require to support safe and effective hemophilia care, has not been located.

Southern Alberta and southeastern British Columbia hemophilia care has traditionally been coordinated by nurse clinicians from the Calgary Health Region Hemophilia Clinic. Rural linkages included telephone consultation with key caregivers (home care nurses, lab technologists, pharmacists and emergency department nurse managers) and mail-outs of written educational materials. Summaries of comprehensive care clinic visits were routinely submitted directly to family physicians. One-time rural home and hospital visits were done in two communities by Hemophilia Clinic team members (nurse clinician, social worker

and physiotherapist) in 2001. While these approaches were speculated to be worthwhile, effectiveness of such learning and resource supports from the perspective of rural health care providers was unknown.

Key Terms

Key terms are defined as follows:

- Learning / Resource refers to information required in preparation of safe and effective hemophilia care delivery. Information may include (but is not limited to) sources that are written, verbal, and experiential.
- Hemophilia (A & B) refers to a deficiency in factor VIII and IX (respectively) affecting about 3,000 Canadians (Hemophilia A in 1/10,000; Hemophilia B in 1/50,000). Hemophilic bleeding of post-traumatic or spontaneous origin may be life or limb threatening. The level of factor deficiency ranges from severe (<1%), moderate (1 – 5%) and mild (5 – 35%) (Association of Hemophilia Clinic Directors of Canada, 1999; Canadian Hemophilia Society, 2001). For the purposes of this study, the definition of hemophilia is limited to these most common types (A & B), as hemophilic bleeding presentation and fractionated concentrate availability are similar. Rare congenital bleeding disorders (i.e. Hemophilia C; Factor XIII deficiency) are not included, as they may present confounding challenges unique to their diagnosis.
- *Hemophilia Clinic* refers to the multidisciplinary, outpatient program offered to children and adults at the Alberta Children's Hospital.

- Comprehensive Care Team refers to the multidisciplinary Hemophilia
 Clinic staff. This team includes registered nurses (3), hematologists (2), physiotherapist, social worker, dentist, transfusion medicine technologists, orthopedic surgeon, program manager and secretary. Team members are affiliated with other programs, and are not dedicated exclusively to the Hemophilia Clinic. A hematologist is available for consultation 24h/day, 7 days/week.
- Hemophilia Treatment Centre refers to the hospital where the Hemophilia Clinic is located (Alberta Children's Hospital). Services including emergency, laboratory, diagnostic imaging, outpatient and inpatient care are most frequently utilized.
- *Rural* refers to those communities beyond a 30-minute commuting distance (Mendelson & Bollman, 1998) to the Hemophilia Treatment Centre located in Calgary. "Long distance to a tertiary care hospital" is recognized by multidisciplinary health care providers as one of the top 5 indicators of rurality (Steering Committee of the Development of a Multistakeholder Framework/Index of Rurality, 2003, p. 11). Census agglomerations above 10,000 are also considered rural for the purpose of this study, given the limited geographic accessibility to designated, specialized hemophilia care for communities beyond the Calgary Health Region.

- Rural hemophilia health care providers refer to multidisciplinary professionals practicing in a rural hospital or community based health program, in a locality with a residing hemophiliac. This may include registered nurses, physicians, physiotherapists, social workers, pharmacists and lab technologists.
- Collaborative refers to a non-hierarchical process that aligns rural and urban providers and families as partners in healthcare planning and service delivery (Gray & Wood, 1991). This partnership is mutually beneficial, recognizing the strengths and capacities of all team members while maintaining the family and patient as central (Amundson, 2001; Institute for Family Centered Care, 2002).

Overview Summary

The research problem at hand related to the lack of evidence supporting resource needs and capacities of rural hemophilia care providers. This presented a significant problem given challenges associated with managing urgent hemophilic bleeding in a setting that is distant from the specialty tertiary care centre. As many families with hemophilia live in communities beyond commuting distance to the tertiary care centre, the underlying purpose of this study was to assist in the safe and effective provision of rural hemophilia care. This problem required systematic investigation of the learning needs and capacities of rural providers as pivotal members in the hemophilia care team.

A review of the literature on hemophilia and rural care as related to the

research problem is discussed in <u>Chapter 2</u>. The literature review includes professional guidelines, conceptual work and research studies relevant to the nature of hemophilia and subsequent provider learning needs, rural health delivery and hemophilia care, and knowledge requirements of rural health care providers in specialty care. <u>Chapter 3</u> is a discussion of the mixed-method research process, including methods, sample, data collection, analysis and ethical considerations. <u>Chapter 4</u> provides a detailed overview of research findings from all 3 research stages. This includes examination of sample, setting, results and development of subsequent research stages. A closer examination of findings related to the research questions is found in <u>Chapter 5</u>. Consideration is given to study limitations, alongside theoretical and research implications. Application of findings related to the development and evaluation of a rural multidisciplinary hemophilia education day is also discussed.

CHAPTER TWO

REVIEW OF THE LITERATURE

Search Background

The review of literature databases encompassed 1966 to present (CINAHL, Medline, PsycINFO and EBSCO Academic Search Premiere) with key words hemophilia (bleeding disorder), rural (remote / outreach), learning (education / inservice / preparation), knowledge, resources, and health (care / providers / service / practice / team). Research findings related to the learning and resource needs and capacities of rural hemophilia health care providers were not located. Given this research gap, the search was expanded to include family resources, professional guidelines, scholarly conceptual publications and research. Topics related to the nature of hemophilia, hemophilia rural care needs, knowledge required for hemophilia care, the nature of rural health care delivery, and preparation of rural providers were reviewed.

Hemophilia

Conceptual Literature

Hemophilia is a lifelong disorder, with challenges related to acute bleeding, chronic illness and potential disability (Beeton, 2002). Hemophilia refers to a deficiency in clotting factor VIII (hemophilia A) or IX (hemophilia B) affecting 1/10,000 and 1/50,000 (respectively) persons of all cultural and ethnic backgrounds (Mannucci & Tuddenham, 2001). Hemophilic bleeding may have post-traumatic or spontaneous origins with life or limb threatening potential. As

the frequency of bleeding is associated with the level of clotting factor deficiency, severe levels are often associated with frequent spontaneous and post-injury bleeding in muscles and joints, whereas mild levels are associated with bleeding from greater trauma (Santagostino, Gringeri & Mannucci, 2002).

Research Literature

Health care needs must be considered for those living with this chronic illness, as hemophiliacs worldwide report overall lower health-related quality of life compared to the normal population as measured by the standardized SF36 instrument (Miners et al., 1999; Aznar et al., 2000; Mohlo et al., 2000; Solovieva, 2000). While physical needs associated with bleeding episodes were well documented, holistic needs of the hemophilia patients and family were also evident in the literature. Hemophilia family roles and coping styles related to bleeding, treatment issues (i.e. venous access), and feeling "different" (Spitzer, 1992, p. 164) have been reported. Grounded theory inquiry (Spitzer, 1992) revealed that children living with hemophilia actively utilized "emotion and problem focused coping strategies" (p. 165). However, coping measurement checklists comparing hemophilia children, parents and typical children (Miller et. al., 2000) indicated that parents adopted active, problem-focused coping skills. and "blamed themselves and others" (p. 11) significantly more as compared with their hemophilic children. While children overall were reported to rely on more passive coping styles like "wishful thinking", a smaller proportion of children with hemophilia adopted this approach. Given the varied experience and impact of

living with hemophilia, health care needs and interventions unique to this population require further investigation regarding quality of life in the dynamic context of health and illness (Beeton, 2002): How to best support this multifaceted need may be best known by those involved in hemophilia care.

Preparation of Hemophilia Care Providers

Conceptual Literature

While it may be concluded that all journal articles on hemophilia serve as potential resources for health care providers, this literature search attempted to identify and review those resources that were specifically identified as health care provider resources. Reviewed articles included literature on hemophilia assessment, treatment and related resources.

This review revealed a series of instructive essays (Waters, 1994 & 1995) that provide step-by-step information for nurses on the assessment and management of hemophilia. Similar content presented in Susman-Shaw & Harrington's (1999) educational article was accompanied by a knowledge quiz for readers. Specific information related to assessment and management of joint bleeding (Orto, 1995), as well as extensive guidelines for broader hemophilia emergency care were located (Bush & Roy, 1995; Coyne & Lusher, 2000) providing reviews of hemophilic bleeding related to diagnosis, clinical manifestations, assessment guidelines, treatment, and specialist resources. Bush & Roy (1995) included a case study and post-test of hemophilia content related to hemophilia diagnosis, genetic transmission, mucosal bleeds, and life and limb threatening

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hemorrhages. These articles were evidence-based, and written from the expert perspective of hemophilia and emergency care professionals.

While the Canadian Hemophilia Society does not provide a distinct reference manual for care providers, their multidisciplinary-produced binder entitled "All About Hemophilia" (2001) presents a comprehensive resource for families: topics covered include hemophilia basics, genetic transmission, comprehensive care, clotting factor therapy, management of bleeds, home infusion, complications, developmental and health promotion issues, and future care issues. The American National Hemophilia Foundation (1995, 2001) has produced orientation manuals specific for hemophilia nurses, physiotherapists and social workers. These orientation booklets provide an overview of knowledge required for those health care professionals embarking in specialty hemophilia care, with content similar to the Canadian Hemophilia Society (2001) binder.

Other available resources designed to support the knowledge base required for hemophilia care include the Association of Hemophilia Clinic Directors of Canada (1999) resource booklet for the diagnosis and treatment of hemophilia, and the American Region VI Hemophilia Nurses (2000) manual on hemophilia emergency care. The World Federation of Hemophilia (2003) also makes available a series of articles on hemophilia and related treatment for health care professionals. These comprehensive resources are available by hard copy and Internet. References cited within such resources suggested that these learning

tools had been developed based on the nature of hemophilia. Nonetheless, evaluation of the impact of such resources on the knowledge base of hemophilia providers was not located in the literature; furthermore, such resources were developed mainly from the hemophilia expert perspective for other health care professionals. This leads one to question if there is a need to develop new resources, or perhaps efforts should be directed at enhancing the effectiveness and implementation of existing resources.

Research Literature

As family-centred care is a collaborative partnership, the family's perspective on the health care experience holds foundational value. Indicators of quality hemophilia care were examined in a survey of 54 families (Cygan, Oermann and Templin, 2002). Using the Quality Health Care questionnaire, parents rated quality care related items on a 5-point scale. Findings indicated the most important aspects of care delivery were related to inclusion in decision-making (M=4.98), and competent care by nurses (M=4.94) and physicians (4.94). These findings are consistent with previously conducted research (Meerpol, 1991; Garwick, Kohrman, Wolman & Blum, 1998; Oermann & Templin, 2000), thus further supporting the notion that preparing and sustaining competent providers is an important facet in the provision of quality hemophilia care as perceived by the family.

Research in the United Kingdom by Minhas and Giangrande (2001) on the presentation of hemophilia in the emergency department suggested a "probable"

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lack of knowledge" (p. 249) amongst physicians, as evidenced by the delay in identifying 80% of cases with severe factor deficiency, requiring that patients revisit medical providers an average of 4.13 times prior to diagnosis. As the most common presentation reported was "easy bruising" rather than joint bleeding, raised awareness on this range of likely presentations may assist with meeting this information need. It was acknowledged that the rare incidence of hemophilia presents an additional challenge for emergency clinicians in the United States as well (Nuss, Hoffmann & Hammond, 2002). However, this challenge must be overcome as early diagnosis is required for initiation of effective treatment and avoidance of unnecessary physical abuse investigations.

An American epidemiological study of emergency department visits by all Colorado males with severe hemophilia over a 1-year period revealed 125 visits by 51 patients (Nuss, Hoffman & Hammond, 2002). Of the emergency assessments, hemorrhage (64.8%, 95% CI=55.6, 73.1) was the most frequent cause for admission. Despite this common presentation by hemophilia patients, errors in hospital care were noted. In 13% (95% CI=6.4, 22.6) of these cases, treatment was indicated but not administered; in 12.3% (95% CI=5.5, 22.8) of emergency admissions associated with administration of treatment, errors were noted in product selection or dose, with complete documentation of factor concentrate infusions found in just 13.9% (95% CI=6.5, 24.7) and 24.6% (95% CI=14.8, 36.9) admissions respectively. While authors noted that prescribing practices and documentation related to emergency hemophilia care require improvement, a recommended solution to this problem was encouragement of emergency physicians to utilize available hemophilia resources. Barriers and facilitators associated with emergency department staff learning needs and utilization of such resources were not reported.

A case study on severe hemophilia-related hospitalization (Cleary, 2003) identified multidisciplinary health providers' learning needs related to specialty hemophilia care in a variable health service environment. Identified gaps included expertise related to hemophilia basic knowledge, factor replacement therapy, assistive devices, pain control, discharge planning, collaborative teamwork and family-centred care. Knowledge gaps were associated with "lapses in attention to patient needs" (p.37), which could be improved by regarding the patient as a valued, central resource for health care providers. Providers should consider ways to reduce transitions and minimize variability in approaches. Cleary (2003) indicated that "expertise and experience" (p.33) provide the best predictors for quality in highly specialized care such as hemophilia (Solomon, Bates, Panush & Katz, 1997).

In a cohort study by Soucie et al. (2000), mortality among hemophiliacs was found to be significantly lower (p = .002) for those who received routine comprehensive care in Hemophilia Treatment Centres. Coordinated, multidisciplinary team assessment at the Hemophilia Treatment Centre was determined to be foundational to effective individual treatment plans and overall illness management (Soucie et al., 2000; Ritchie, 2002). Comprehensive care of

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families living with hemophilia supports the main therapeutic goal to prevent and control bleeding episodes (Santagostino, Gringeri & Mannucci, 2002).

Rural Hemophilia Care

Conceptual Literature

No research literature specific to the provision of rural hemophilia care was located. The National Hemophilia Foundation (2003) identified rural families needing to travel distances of greater than 2 hours to the hemophilia treatment centre to be "at risk and underserved" (p.4). Mobility restrictions and timely management of bleeding (Bush & Roy, 1995; Association of Hemophilia Clinic Directors of Canada, 1999; Miners et al., 1999) necessitated access to supplemental rural health care services by people with hemophilia who live beyond commutable distance to the Hemophilia Treatment Centre. Pain, mobility and physical restrictions were noted to be particularly significant (p < 0.001) for severe hemophiliacs (Miners et al., 1999). In consideration of such hemophilic challenges, accessibility to rural health care resources was a noted requirement for both acute and chronic health care management. Rural hemophilia health care as an enhancement (not as a replacement) to existing comprehensive care programs was recognized as consistent with cornerstones of the Canada Health Act: comprehensiveness, portability, universality, accessibility and public administration (Canadian Nurses Association, 2002).

Research Literature

Needs assessments on Canadians with hemophilia identified themes relating to the challenge of accessing rural health care services with related expertise (Taylor, 1999; University of British Columbia, 2001). Rural health care providers were reported to face known challenges related to hemophilia care: assessment, treatment, intravenous access, fractionated blood products, hepatitis C and HIV (Association of Hemophilia Clinic Directors of Canada, 1999; Taylor, 1999). Such challenges are accentuated by geographic isolation and limited access to resources as experienced by rural providers (Pong, 2000; Aday et. al, 2001).

Rural Health Care Delivery

Conceptual Literature

Isolation and distance from urban centres provides an initial appreciation of the rural patient and provider context. This geographical positioning has been further associated with the rural population's predominantly self-reliant approach to health-related issues, with subsequent adherence to local informal support systems (Long & Weiner, 1989; Goins & Mitchell, 1999). Such mutually reliant confines of rural community life propagate a blurring of personal and professional boundaries, thus predisposing both patients and providers to a relative lack of anonymity in health care delivery (Long & Weiner, 1989; Baird-Crooks, Graham, & Bushy, 1998; MacLeod, Browne & Leipert, 1998). These key facets must be considered in the appraisal of needs and capacities in rural health care delivery. According to MacLeod (1999), rural providers have difficulties in assuming care directed by urban health practitioners, particularly because of the limited awareness of the unique challenges faced in rural health care delivery. As policies, procedures and standards developed by urban teaching hospitals may not be suitable to the rural setting (MacLeod, 1999), local approaches may enhance sustainability and capacity building of health care delivery (University of Northern British Columbia, 2002). Ramp (1999) described the rural context as unique, requiring due consideration in the design and delivery of health care programs. In particular, a need to address fragmentation of system services and barriers related to provision of care has been identified (Troughton, 1999). Partnerships established with rural providers that reflect local practice realities, and build on strengths of the community, have been posited to facilitate effective health care delivery (Kulig, 1999; Walker, 1999).

Overall, rural hospitals are expected to collaboratively meet the range of needs existing in the community served with an alliance of care networks (Moscovice & Wellever, 2001; Nesbitt & Kuenneth, 2001). Details of how this alliance of specialty clinic, rural providers and families may facilitate such expectations in rural hemophilia care have not been located in the literature. The family has been recognized as a member of the rural health care team, with active participation in decision making, planning and holistic outcome monitoring as facilitated by health care providers (Rosenthal & Campbell-Heider, 2001). While emergency care may be available for hemophilia families living in rural

communities, consideration has been given to the local service capabilities and relative frequency of hemophilia related admissions (Minhas & Giangrande, 2001; Nuss, Hoffman & Hammond, 2002). Successful rural emergency systems were deemed to require easy accessibility with coordinated communication links, trained response team, rapid emergency transportation, and effective connections to higher levels of care (Williamson, 2001). Effective preparation for competent specialty rural care delivery was thereby surmised to be facilitated through the self-identification of learning and resource needs and capacities of rural hemophilia health providers.

Learning Preparation of Rural Providers in Specialty Care Conceptual Literature

As continuing competence is required for all health care professionals, it was fitting to address the learning and resource needs and capacities of rural hemophilia health care providers. Identifying such needs and capacities from the provider perspective was noted to be a foundational requirement to effective and sustainable preparation for hemophilia rural health care delivery. Barriers experienced by rural providers related to participating in continuing education included time, distance, cost and staff replacement difficulties (Bushy, 2000; . Rourke, 2001). While communication technology such as the Internet may be helpful to reduce such barriers, the challenge was identified for multidisciplinary rural health professionals to acquire adequate support and education for skill development in their multiple, overlapping roles (Bushy, 2000).

Research Literature

While no studies were found to support the resource requirements of rural hemophilia multidisciplinary providers, research was located in other general and specialty care areas. A cohort study with Australian rural and remote nurses (Bell, Daly & Chang, 1997) identified overall educational and research priorities by way of a Delphi survey. Educational priorities included experiential learning associated with urban clinical placements for rural nurses and "hands-on" midwifery skills; additional learning priorities included counseling skills, treatment of asthma and general upgrades in areas of specialty care (i.e. burns, ulcers, diabetes) (p. 798). The problem of professional isolation shared by rural and remote nurses was reiterated, with recommendations to investigate effective strategies for provider education. Nurses identified education as a requirement to preparing competent caregivers for effective health service delivery (Buckley & Gray, 1993).

A Canadian needs assessment (Barnabe & Kirk, 2002) on palliative care education for rural physicians revealed adequate knowledge of symptom management. Less confidence was reported on knowledge of psychosocial care related to issues such as bereavement. Emerging themes from semi-structured interviews suggest physician interest in roles related to continuing education, multidisciplinary teamwork and patient-centred care. Physicians indicated a preference to access learning opportunities on this specialty care area at a nearby location. Preferred learning methods included case studies, lectures and self-directed learning modules. While this information is not widely generalizable to other contexts, findings were interesting given the expressed need for collaborative and holistic care resources that have flexibility and proximity to the rural health care provider. This self-identified requirement by rural physicians for ongoing professional development beyond continuing medical education was recognized in a previous Australian needs assessment project (Booth & Lawrance, 1998).

Evaluation of a continuing education program for rural cancer care physicians was conducted over a 4-year, randomized controlled trial in 18 American communities (Elliott et al., 2002). Context specific strategies in this multi-modal, previously tested curriculum for rural medical cancer care were evaluated based on desired aspects of physician practice related to diagnosis, staging, treatment, research participation and patient follow-up. Findings demonstrated this continuing education intervention as having no significant impact on improving practice. Of interest, authors have speculated that education developed by specialty care clinics may not effectively translate to rural providers. This conclusion is of interest to the current research project and process, as rural providers' self-identification of their learning and resource needs is viewed as foundational to successful preparation for rural specialty health care delivery. While expert knowledge of those regularly enmeshed in hemophilia care is noted with due regard, the needs and capacities of rural providers are thought to best be defined at the source to ensure development of meaningful resources: such

resources are required to support safe and effective hemophilia family-centred care in the rural setting.

Conceptual Frameworks for Rural Hemophilia Care

A framework specific to learning and resource needs of rural health providers in hemophilia or specialty clinic care was not located in the literature. Nonetheless, this research process has been informed by concepts that reflect current practice in outpatient specialty clinic care. This includes Family-Centred Care (Institute for Family-Centered Care, 2003), Transition Mid-Range Theory (Meleis et al., 2000) and the Supportive Care Model (Oberle & Davies, 1993). The research process has been informed by concepts founded in these models. While all three frameworks have distinctive underpinnings and application possibilities, the fusion of such knowledge provided a synergistic view of the dynamic and interwoven facets in rural hemophilia health care delivery. Congruent with the reviewed literature described above, these key concepts included persons, locations and situations that are contextually bound and therefore require adaptable approaches to service delivery. Such conceptual frameworks will be explored with reflection on the identified research problem related to rural hemophilia health care.

Family-Centred Care

Although the individual with hemophilia is officially referred to as the patient, the whole family is regarded as the unit of intervention as their shared experiences are central in health and illness management. Embracing a family-

centered care philosophy, care must reflect guiding principles of respect, open communication, self-efficacy and collaboration by way of "mutually beneficial partnerships" shared by children, families and multidisciplinary providers (Institute of Family-Centred Care, 2003). Family-centred health related interventions are not limited to the tertiary care hospital, and may extend to the homes and communities of the family as required. According to the Institute for Family-Centred Care (2003), this approach is distinguished in its "planning, delivery and evaluation of health services that are administered by way of mutually beneficial, collaborative partnerships between health care providers, patients and families" (p.1). The Institute for Family-Centered Care states that the 4 key elements of family-centred care include:

- Treatment of persons with dignity and respect;
- Communication of complete and unbiased information in an affirming and useful approach;
- Capacity building by building on strengths and participating in experiences that facilitate independence; and
- Collaboration shared amongst patients, families and health care providers in development of policies, programs, professional education and care delivery. (p. 1)

While the key elements of this philosophy may be succinctly distilled, practical application of this approach has revealed complex challenges related to historic professional-centred patterns of health care service delivery (Ahmann, 1994).

Nonetheless, this philosophy is congruent with the present focus of the Calgary Health Region to provide excellence in family-centred care (Calgary Health Region, 2003). Integration of this philosophy to practice is an emerging effort in the health care environment where the hemophilia clinic is situated. Furthermore, as the family-centred care philosophy matches my own ontological view, such underpinnings are inherent to the examination of the research problem at hand.

Mutually beneficial, family-centred partnerships serve to address needs and build on capacities. Within this partnership, unknown learning and resource needs and capacities of rural hemophilia providers are viewed as a problem affecting what is of central importance in health care delivery: the service of patients and families. This problem is a distinct element that exists as part of the larger, interwoven system of family-centred health care delivery.

Transitions

Health and illness experiences require ongoing adaptation, given the associated transient periods of equilibrium and disequilibrium (Thomas, 1992). According to Meleis et al. (2000), such transitional stages are regarded beyond concepts of coping and adaptation given the opportunity for enhanced wellness amidst increased vulnerability. The nature of transition phenomena is biophysical and psychosocial, as evoked from critical experiences with physical illness and health, developmental changes, and organizational, situational and environmental factors (Qualls, 1997; Meleis & Trangenstein, 1994). The provocation for transition may be insidious or related to a critical event. Given the

broad range of associated holistic experiences, it is not surprising that transitions themselves may be compounding. Barriers and facilitators of the transition process include interpreted personal meanings, knowledge, cultural and societal beliefs, and socioeconomic status (Meleis et al., 2000). To appreciate evolution within the transition experience, one must look for associated developing confidence and effective coping skills. Examination of the transition process provides significant awareness of the whole-person experience, as adaptability and transformation of roles provide indicators for illness management and health promotion (Pridham, 1998).

As families assume an active role in health transformative processes, collaborative family-centred partnerships include relations with care providers. This thinking extends to the subsequent requirements of health providers to facilitate families' transformative growth: in order to provide such support effectively, health care providers must be adequately prepared to care for families within a dynamic context. Furthermore, trusting relationships congruent with principles of family-centred care are fostered by the providers' expertise in their service with families. It is therefore important to understand the associated learning and resource needs and capacities that are required in the preparation of providers to foster trust and facilitate transformative growth of families. It is understood that as the experiences of the family evolves, so will the preparation requirements of the health care providers.

Supportive Care

Partnerships are inherent to the "Supportive Care Model" (Oberle & Davies, 1993) as preservation of integrity is the central goal of care. This approach reflects the fluidity required to facilitate transformative growth in health service delivery, as the context of each family's experience is tailored within the dimensions of "connecting, empowering, finding meaning and doing for" (Oberle & Davies, 1993, p. 68). While "doing for" may be misinterpreted as a lack of partnership, this core dimension reflects the realities of service regarding the need for dignified care of families who are unable to care for themselves or require extrinsic resources: this is a partnership based on trust and honor. This model respects dynamic partnerships within the care continuum, ranging from professional health care provider as monitor, facilitator, and complete dependent care provider, as per the needs and capacities of families. This approach is well suited to support therapeutic relationships as supportive care dimensions vary in emphasis as required by the family unit.

With "valuing" and "preserving integrity" as encompassing and central dimensions respectively, such intrinsic respect and responsiveness provides a framework that supports the creation of "mutually beneficial partnerships" in Family-Centred Care (Institute for Family-Centred Care, 2003, p.1). While the family is regarded as central, multidisciplinary professionals are also supported by the explicit recognition to preserve provider integrity by way of matching professional beliefs with praxis. Preservation of integrity is central to this model,

illuminating the effective partnership potential shared between family and health care professional. The Supportive Care framework is truly "mutually beneficial" given the complementing needs for families to receive, and for health professionals to provide effective, meaningful care. This model is thereby recognized to provide a fitting, foundational approach to the research process by reflecting the interconnected dimensions of care by all key participants.

Summary of Conceptual Frameworks

While this overall conceptual approach is family-centred, it is also inherently reflexive for the health care provider given the simultaneous experiences of his or her own professional and personal journey. While health care providers are charged with the duty to relate to the individual and family, the provider must also reflexively recognize self as a person within his or her own context. This view allows the health care provider to challenge assumptions and examine held beliefs and knowledge with subsequent deliberate application to practice. Furthermore, this promotes meaningful partnerships that are responsive for each family and situation. Health care providers' own transformative growth comes from reflection and acknowledgement of needs and strengths required for safe and effective supportive care.

This synthesis of philosophy and theory provides an overall conceptual framework that regards the research problem as inextricably linked to the ultimate purpose of health care delivery. Health care providers' primary objective is to serve the health and illness management needs of families. While the

family is regarded as central, relationships shared with families and providers are guided by mutually benefiting principles: the provider role in health service delivery is thus viewed from a collaborative partnership perspective. However, preparation requirements of rural hemophilia providers must be understood if they are to develop their expertise in family-centred care. Therefore, learning and resource needs and capacities of those serving hemophilia families must be considered within a dynamic context to better understand how health providers may collaboratively impact supportive, family-centred care. Moreover, a foundational qualitative approach is required to address this research problem to openly appreciate the perspective of rural hemophilia providers regarding their own needs and capacities. Once this perspective is understood, it is then fitting to quantify such emerging themes.

Literature Review Summary

Learning and resources required by multidisciplinary health professionals to provide specialty hemophilia care in a rural setting have not been located in the literature. Nonetheless, previous studies have illuminated several key points that are relevant to this research process. First, service provided to hemophilia families must address their needs as central, based on holistic health and illness experiences. Second, health professionals called upon to care for hemophilia families are challenged to prepare themselves to provide competent care within their scope of practice. Third, hemophilia families and professionals alike have reported unique, compounding challenges associated within the nature of rural
health care service delivery, thus necessitating an appreciation for this context from the source. Finally, the preparation for rural providers in specialty care areas is recognized to exist amongst competing needs, hence requiring an efficient approach to ensure knowledge transfer. These key points located in the literature are linked by the conceptual frameworks and support the purpose of this exploratory study: to identify the learning and resource needs and capacities of rural hemophilia health care providers such that they can be better prepared to provide safe and effective health care delivery.

Research Questions

Primary Question

1. What are the learning and resource needs and capacities of rural hemophilia health care providers?

Secondary Questions

2. What do rural hemophilia health care providers identify as barriers and facilitators regarding linking with the Hemophilia Treatment Centre comprehensive care team as a resource?

3. What do rural hemophilia health care providers identify as barriers and facilitators regarding treatment with fractionated blood products?

CHAPTER THREE RESEARCH METHODS

Study Design

Using a multi-method design, three stages of research were conducted: focus group, semi-structured key informant telephone interview and mail-out survey (questionnaire). This approach was deemed appropriate as the research questions require initial open exploration of concepts, necessitating a gradual shift from qualitative to quantitative data collection and analysis. This successive study progressively identified outcome variables and content required in data collection tools. The primary outcome variable was identification of learning and resource needs and capacities of rural hemophilia health care providers. Data collection was conducted in the focus group through narrative documentation by recorder and audio-tape, semi-structured interview through narrative documentation by interviewer, and self-report, mail-out survey by way of a postal survey.

Sampling Plan

Purposive sampling was implemented for key informant focus groups and telephone interviews, as those to be recruited were judged as most knowledgeable regarding the issues to be studied; this is appropriate when using key informants to explore needs assessment or tool development (Polit & Hungler, 1999). Convenience network sampling was used for the mail-out survey to ensure that eligible health care providers who were not explicitly

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identified by key informants had an opportunity for recruitment. The target population consisted of multidisciplinary providers typically involved in rural hemophilia care delivery. This population was accessible to the investigator given my dual role as nurse clinician for the Hemophilia Clinic.

A purposive sample was recruited for focus groups (target recruitment of 8–12 participants) and telephone interviews (target recruitment of 9-12 participants), while a convenience sample was invited to participate in the mail survey (N = 200). Each sample group was multidisciplinary. All together, the sample included registered nurses, physicians, social workers, physiotherapists, lab technologists and pharmacists practicing in 11 southern Alberta and southeastern British Columbia rural communities with a residing person with hemophilia. Given previous telephone contacts with providers in each of the rural communities, 64 key informant health care providers were identified with an added network sample of 136 providers (based on staffing approximations by select key informants). This led to an estimated potential sample of 200 providers. Sample size was limited by the number and place of residence of people with hemophilia in this catchment area.

Stage I - Focus Group

Sample

Recruitment for focus group participation was done by initial telephone contact with nurse managers and mail-out of recruitment poster (see Appendix A) with a target of 4-8 participants for each focus group (Kitzinger, 1995): Follow-

up clarification of process and scheduling was done by e-mail, as this method was identified by key informants as a preferred method of communication. Consent was reviewed with participants prior to starting the focus group interview (see Appendix B). The sample recruitment aimed for key informants from a variety of disciplines who were known to each other (Bender & Ewbank, 1994). This sample was desired, as discussion generated among various individuals working together was required to identify the needs and capacity of the entire team. The sample was drawn from each of 2 distinct rural communities with combined experience encompassing pediatric and adult hemophilia care. Two groups of 5 and 6 participants respectively were recruited.

Data Collection

Focus group interviews were held on the same day, morning and afternoon, at 2 rural hospitals in distinct communities within the same health region. At each site, the meeting room used was selected by the local nurse manager. The interview was conducted by a facilitator and a recorder (Bender & Ewbank, 1994). Participants, facilitator and recorder were seated together around a large rectangular boardroom style table. Scheduling arrangements heeded recommendations provided by the nurse educator, with regard to selection of focus group date, time and location. Food and refreshments were provided for participants: doughnuts and coffee for the morning session, and sandwiches and juice for the afternoon session.

Focus group discussion was facilitated by the investigator: a Master of Nursing student with related experience including focus group method workshop attendance (including role playing), previous involvement as a focus group recorder and facilitator, and over 15 years of multidisciplinary team work. Recording was done by a research assistant: a Master of Nursing student with experience in documenting narrative. Sessions lasted for 60 – 90 minutes as suggested by focus group theory (Kitzinger, 1995). At the outset, a few minutes were dedicated for introductions and brief social conversation. Prior to the group discussion (see Appendix C), the facilitator reviewed consent related issues and conveyed that participation was voluntary and would be reported anonymously. This was followed by review of the overall research process and focus group conduct rules. Such rules included confidentiality of the interview discussion content and respect for persons and comments offered. Time was allocated for initial guestions regarding these introductory items. Once consent forms were reviewed and signed, the group discussion began.

Facilitation preparation and discussion strategies were founded on maintaining both the discussion purpose and participants' integrity. Given that the facilitator was also the hemophilia nurse clinician, special consideration was given to strategies for potential digression related to advice seeking by participants on current hemophilia care issues. Prior to focus groups, discussion questions, approach and related strategies were reviewed with members of the research team.

Recording was done by audiotape, and key proceedings were documented directly onto a laptop computer by the research assistant. Discussions were audio taped and comments were entered by the recorder directly onto a laptop computer. Audiotapes were not transcribed verbatim given the required level of analysis. Nonetheless, audiotapes were reviewed and compared with interview minutes and field notes. The recorder took handwritten field notes before and after the focus group to describe the setting and participant interactions. Field notes were based on immediate setting, participant interactions and institutional context. Within 15 minutes after each focus group, the facilitator and recorder held a debriefing session to review the focus group discussion and contextual observations: these discussions were shared over at least 30 minutes while driving from the rural focus group site, and were added to the field notes. Overall, this method of data collection was required for baseline identification of needs and capacities and was congruent with the team approach in hemophilia health care delivery (Rothe, 2000; Hawe, 2001).

Analysis

Qualitative content analysis was undertaken with first-level coding (Altheide, 1987; Priest, Roberts & Woods, 2002), comparing individual and group comments (Kitzinger, 1995). The two main analytic categories were *needs* and *capacities*. First-level coding identified master codes of emergent themes from transcripts and field notes by way of reduction and analysis of the group discussion content; manifest content (direct comments) provided foundation for

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deeper analysis of latent content (meaning within messages)(Berg, 2001). From this initial reduction, "core constructs" were further coded into categories (Priest, Roberts & Wood, 2002, p. 34).

Themes and patterns were considered within the context of the focus group participants and setting (Creswell, 1998). *Themes are defined as textually represented topics or ideas, including perspective, beliefs and feelings; a theme is recognized as a simple expression consisting of a subject and predicate* (Berg, 2001, p. 246). The recorder initially carried out substantive first-level coding of focus group minutes and field notes. This process involved taking a copy of the transcripts and field notes, cutting out words, phrases, and sentences, and sorting them into groups with similar themes (Bogdan & Biklen, 1992). These themes were reduced to groupings based on content emerging from the transcripts, and context as interpreted in the field notes (Creswell, 1998).

Field notes and transcripts were shared with facilitator, research assistant and faculty to bring greater understanding to the context of the focus groups. Reduced and analyzed content groupings were in accordance amongst the recorder, facilitator and nursing faculty. Investigator triangulation permitted a convergent analytical review of findings, promoting a greater substantive and dependable view of generated themes (Denzin, 1978, Berg, 2001). Themes generated in the focus groups provided the foundation for additional probing questions used in the next stage of research (telephone interview).

Stage II- Semi-structured Telephone Interview

Sample

Recruitment was done by a cover letter (see Appendix D) mail out to rural health care providers, with sought representation of all the different disciplines involved in hemophilia care. Names and contact information of potential recruits were known to the student investigator given her dual role as Hemophilia Nurse Clinician. Two weeks later, telephone contact was made by the interviewer at the participant's place of employment with the option for immediate telephone interview. A sample of 3-4 participants was targeted from each of 3 distinct health regions (total target sample 9-12 participants). Regions were selected to represent geographically diverse areas to the west, east and south of the Calgary Health Region. Within 2-4 weeks of the cover letter mail out, telephone interviews were conducted with 3 participants from each region (n=9) representing nursing, social work, physiotherapy and lab technology.

Data Collection

Telephone interviews were selected as a feasible, effective method of reaching key informants from various locations regarding specific data collection (Polit & Hungler, 1999; Streubert & Carpenter, 1999). Guided by baseline information from focus groups, semi-structured telephone interviews were led by the investigator. Interview length was expected to be 15 – 20 minutes given the nature of the interview and work life demands of key informants, with interview length adapted as required. Interview questions (see Appendix E) were

designed to be easy to answer, and elicit meaningful responses in a short period of time (Rothe, 2000).

Telephone interviews ranged in duration from 15 – 30 minutes, based on the willingness and availability of participants. The estimated time frame was initially established between the interviewer and participant, and after 15-minutes the participant was asked if he or she desired to continue to ensure comfort in continuation for extended interviews. The interview was designed to help participants elaborate and clarify themes that emerged from the focus groups. The telephone interview was conducted with consideration to maintaining the consistency of questions between interviews while incorporating the flexibility required for this method of inquiry (Morse, 1989).

Data collection preparation was important given the simultaneous role of the investigator as interviewer, recorder and hemophilia nurse clinician. The investigator made an active effort to be open to respondent's views and yield "knowledge and experience" to comments shared by the participants (Morse, 1989, p. 174). Interpersonal skills were also considered with regard to developing an effective rapport and utilizing question techniques (such as probing and reflecting) that would facilitate a meaningful discussion (Berg, 2001). Further consideration was given to the data entry process, as this required the interviewer to function also as data recorder. Telephone interviews were conducted using a portable telephone headset, allowing the investigator simultaneously to converse and document comments verbatim onto a desktop

computer. Immediately after the interview, laptop recorded notes were reviewed and field note observations were added.

Analysis

Qualitative content analysis was undertaken initially by the telephone interviewer, with subsequent review of transcripts and analysis of selected parts to verify the coding process with the supervisory committee. First and secondlevel coding of themes was carried out as indicated with the main analytic categories of *needs* and *capacities*. The interviewer conducted substantive firstlevel master coding by sorting words, phrases, and sentences with similar themes and grouped accordingly (Bogdan & Biklen, 1992). Sorting was done using Microsoft Word® options that allowed highlighting of similar themes and grouping of words with shared meaning. Themes were reduced to the eight groups established in the focus group analysis, with a ninth open for emerging data. Saturation of categorical groupings was noted, as the same "core constructs" (Priest, Roberts & Wood, 2002, p. 34) were repeatedly stated by participants. Furthermore, no new themes were revealed. Therefore, findings were adequate to inform the next stage of research: survey item development.

The above category groupings were defined as an alignment of themes with recurrent patterns and processes that retain common core properties (Berg, 2001; Priest, Roberts & Woods, 2002). Categories were based on patterns emerging from the interview data and compared with analysis of focus group transcripts. Thematic groups were systematically reviewed and collapsed to five

core categories by way of reduction and analysis of manifest and latent transcript content (Miles & Huberman, 1994, Berg, 2001). Second-level coding ascertained core themes; refined criteria collapsed the eight thematic groupings to five core categories. This level of coding was carried out by way of further detailed interpretation, aggregation and reverse substantiation of interview data to determine foundational themes and sub-themes (Priest, Roberts & Woods, 2002). From the previous themes and any additional ones identified through the telephone interviews, additional specific items were added to the survey.

Stage III- Mail-out Survey

Sample

Recruitment was done by posters at local hospitals (see Appendix F) and mail-out cover letter and survey package to known rural multidisciplinary hemophilia health care providers (see Appendix G). Recruits were identified by the investigator given her dual role as Hemophilia Nurse Clinician. The investigator estimated a target population of 200 rural health care providers, with a projected response rate of 60% (n = 120). Potential subjects were identified through the Calgary Health Region Hemophilia Treatment Centre caseload database, regarding contacts of rural hemophilia health care providers. This database is accessible to the investigator as nurse clinician for the Hemophilia Clinic.

This study included health care providers who were actively practicing as a: a) Registered nurse, physician, physiotherapist, social worker; OR

b) Pharmacist or lab technologist with experience in issuing/ storing/ managing fractionated blood products.

Above included health care providers practicing in communities beyond a 30 minute driving commute to Calgary within:

a) Southern Alberta or southeastern British Columbia communities served by the Calgary Health Region Hemophilia Clinic; and

b) Hospital or community based health program serving a residing hemophiliac. This study excluded health care providers who were practicing within the Calgary Health Region.

Data Collection

Survey Tool Development

The survey tool (see Appendix H) was based on data generated from focus groups and telephone interviews, literature sources, expert panel review, and pilot test. Items were simple, brief, specific and non-leading. Both open and closed formats were used (McColl, Jacoby, Thomas, Soutter, Bamford et al., 1998). Sequencing of questions was from general to specific to assist with clarifying meaning as the survey progressed (McColl et al., 1998). Visually the survey was uncluttered, with consistent format throughout (Dillman, 1991). The tool included a demographic and clinical practice profile checklist, 5-point Likert rating scales and open questions to further explore the context and meaning of closed items identified and to identify further items.

Directions were clearly indicated in each section (Dillman, 1991; McColl et

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al., 1998). Open items were included in the survey to gather data that may not have been identified in the focus groups or telephone interviews. Closed items were included to gather data in a method that could be consistently measured within and between participants (Polit & Hungler, 1999). Such closed items were used to confirm themes that had been identified in the previous stages of research (focus groups and telephone interviews).

The tool was initially edited by 2 nurses from the hemophilia clinic for content; furthermore, 2 undergraduate nursing students completed the tool as a preliminary check for ease and time required for completion of survey items. Following this initial step, the survey tool was e-mailed to 5 members of an expert panel, requesting an individual review of tool clarity, content and structure. Comments were provided directly on the survey itself. This expert panel consisted of 2 University of Calgary Faculty of Nursing professors (distinct from the faculty investigators) with noted expertise in instrument development, one Canadian Hemophilia Society representative, and 2 members of the Calgary Health Region, Hemophilia Clinic (distinct from the investigator).

Once expert panel recommendations were incorporated into the tool, a survey pilot test was conducted with 6 hemophilia emergency care providers of different disciplines from the Calgary Health Region (excluding Hemophilia Clinic staff). These volunteers were recruited from the Alberta Children's Hospital, as they were accessible to the student investigator yet excluded from the study proper. Rural health care providers were not included in the tool pilot test to reduce

response bias. Copies of the survey were hand-delivered to the hospital department, and the process for pilot test was reviewed with the attending charge nurse. The charge nurse then recruited available staff to complete the survey. Pilot test participants completed the survey, and tool completion was reportedly done within the estimated 15 minute time frame. Surveys were returned to the student investigator that same day. Further comments were noted directly on the survey regarding tool clarity, and recommendations were incorporated to the survey.

Saliency and relevance of the tool for respondents was indicated in the cover letter and survey. Tool validity of all survey items was established through several steps. Content validity was assured by the use of focus groups and telephone interviews to augment literature review and the clinical experience of the Hemophilia Clinic nurse clinician. Content clarity was established through tool review by the five member expert panel and pilot test of all survey tool items.

Five main sections defined the overall survey structure, including demographics, learning needs and capacities, connecting with the hemophilia clinic, treatment with fractionated blood products, and possibilities for supports. Items were designed to reflect the five thematic categories that emerged from the first 2 successive research stages: objective knowledge, subjective knowledge, communication, team roles, and partnerships. Closed-ended questions required three responses relating to identification of item importance (yes or no – nominal level data), rating of item importance (5-point Likert scale –ordinal/interval level

data) (Garson, 2004) and identification of item application within current practice (yes or no – nominal level data). Open-ended questions (6 items) solicited comments within each main section and sought to include ideas that may not have been captured in the defined closed questions.

Survey Tool Implementation

The survey mail-out plan included a return, addressed and postage-paid envelope. A modified Dillman (1991) technique to enhance survey response rate was applied by mailing a follow-up "thank you letter" 2 weeks after survey mailout (see Appendix I). This letter served as both a reminder for survey completion and appreciation for participation. An invitation to attend a complimentary oneday workshop in Calgary for rural hemophilia health care providers was included in the package (see Appendix J). Respondents were asked to send their education day responses by fax so that there would be no identifiers in their completed, mailed-return surveys. It was made explicit in the invitation that participation in the workshop was not dependent in any way on participation in the research. Surveys were returned by first class mail to the University of Calgary, Faculty of Nursing research office (Southern Alberta Nursing Health and Research Resource Unit).

Analysis

The survey was a 94-item tool that combined 88 closed-ended and 6 openended questions (see Appendix H). Closed survey items were coded by the student investigator and recorded on a master list, and data headings were

entered into a statistical software program (SPSS® version 12). This program was utilized to generate descriptive and inferential statistics, including item frequency, rating, cross tabulation and comparison of means. This analysis approach is consistent with survey design and research questions. Data entry was done by a research assistant (undergraduate nursing student). Random data entry checks were done by the MN student investigator to ensure adequacy. Open questions were entered into Microsoft Word® for content analysis. Assistance with statistical analysis was provided by 2 mathematics professors from the University of Calgary.

Demographics were reported as a whole and aggregate groupings relating to profession and hemophilia related experience; location demographics were entered but not explicitly reported to ensure anonymity. Frequencies of nominal variables were computed and compared within and between groups by occupational strata, comparing nursing with non-nursing care providers. Fiveitem Likert scale ratings of importance (mean) were interpreted as interval level data (Garson, 2004) and compared within and between groups. Items reflected learning and resource needs previously identified in the five thematic categories that emerged from the first 2 research stages. Ratings of "high importance" were interpreted based on scores of equal to or greater than 4 (scale of 1-5). Ratings of item importance (mean) were then compared within groups with item availability in current practice: a "need" was interpreted as a statistically significant difference between the two means, whereas a "capacity" was

interpreted as a statistically significant correlation. First-level coding by content analysis was used to interpret responses in the open ended questions. In this analysis, themes were grouped based on the 5 main categories that emerged from the first 2 research stages; open categories were also noted for new emerging themes.

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Inferential statistics were used to look for relationships within and between groups of nurses and allied health regarding the 5 categories identified in the first 2 stages of research. Parametric tests used included 2-tailed t-test (Polit, 1996; Garson, 2004). Non-parametric tests included contingency tables (Chi Square), Wilcoxon-Signed Ranks and Spearman's Rank Correlation (Polit, 1996). Nonparametric and parametric tests were compared to ensure consistency in findings.

Ethics

Ethical principles (University of Calgary, 2001) were considered throughout the research process. *Respect for persons* was foundational in recruitment, data collection and analysis as study participation was voluntary, responses confidential (i.e. focus group rules of conduct reviewed importance of group confidentiality), and surveys (including return responses) were sent by first class mail. Furthermore, all research data has been stored in a locked cupboard at the University of Calgary, Faculty of Nursing; audiotapes will be erased and notes will be shredded within 5 years of study completion. Principles of *nonmaleficence* were adhered to, given the minimal risk (no real harm) associated with participation in focus group, telephone interview or survey. Furthermore, the guiding principle of *beneficence* was noted, given the associated benefit to respondents in providing evidence to guide development of educational programs and resources to support effective rural hemophilia health care delivery.

The plan for initial recruitment contacts through the student investigator was discussed at the time of protocol development with the Office of Biomedical Ethics. With the focus being on needs assessment and rural capacity building rather than program evaluation this arrangement is not seen as putting respondents in a vulnerable position. By virtue of the investigator's position as the Hemophilia Clinic nurse clinician, individuals recruited were known yet survey data were coded in such a way that neither investigator nor research assistant knew the identity of respondents. Return envelopes and follow-up mail-out was handled by the research assistant. The use of mail-out survey as such was advantageous in that respondents were allowed greater anonymity (McColl et al., 1998).

Research methods were purposively selected based on suitability given the research problem and questions, with attention to internal validity throughout the research process. Such method selection was guided by the underlying research purpose to create foundational awareness of rural hemophilia health care provider learning and resource needs and capacities, with potential generalization of this protocol to other Canadian rural areas. Methods selected

were inline with accessible sample recruitment, as contact information was accessible to the student investigator. Focus group consent (see Appendix B), telephone interview guidelines (see Appendix E) and survey cover letter (see Appendix G) contained comprehensive information to inform respondents about study participation. As survey responses were anonymous, the cover letter indicated consent implied with survey return.

Research Methods Summary

The research process was guided by scholarly conduct and ethical principles, as reflected in sampling recruitment, data collection and analysis. Results from each stage served to inform data collection tool development for the succeeding research process. As each stage of the data collection process incorporated emerging themes and related questions, data collection tools also required iterative and successive development. Overall, this proposed method was adhered to throughout the research process.

CHAPTER FOUR RESEARCH FINDINGS

Timeline

Data collection for this study was initiated September 2002 with completion in March 2003. Focus groups were held in September 2002, telephone interviews in October 2002, survey mail-out in February 2003, and reminder letter in March 2003. While the original protocol had indicated completion of data collection by December 2002, this schedule was extended as the first two stages of data collection were completed later than anticipated. Protocol modification to a later date was approved by the Office of Bioethics for an extension of March 2003 (see Appendix N).

Stage I - Focus Group

Sample

Focus group interviews at 2 rural sites in southern Alberta were held in local hospital meeting rooms. Meeting rooms were chosen by the nurse manager from each site and were familiar to all participants, thus facilitating comfort for focus group dynamics (Kitzinger, 1994). Site 1 was located in a community of approximately 1,000: this community was situated over 30 minutes commuting distance from Site 2, and had 8 acute care beds and 24-hour emergency service. Residing persons with hemophilia at Site 1 consisted of 3 children with severe hemophilia. Site 2 was located in a community of approximately 10,000 persons, and situated over 30 minutes commuting distance from Site 2 was located in a community of approximately 10,000 persons,

care beds and 24-hour emergency service. Residing persons with hemophilia at Site 2 consisted of 4 adults ranging from severe to mild hemophilia.

Both sites had representation from nursing, medicine and lab technology. While focus group posters invited all disciplines to participate in these sessions, representation was not obtained from social work, physiotherapy or pharmacy. Site 1 did not have social work and physiotherapy employed as hospital staff. Total of *N*=11 participated in this initial research stage (*n*=5 from site 1; *n*=6 from site 2).

Themes

Eight thematic groupings emerged from focus group discussion: objective knowledge, subjective knowledge, roles, limits, communication, trust, teamwork, and growing partnerships. Thematic groupings represent data sets of ideas that were recurrently expressed by participants as key facets in providing effective rural hemophilia care: these themes emerged from the qualitative research process and were not preconceived. Within such defined areas of importance, <u>needs</u> were interpreted as items that are not being met while <u>capacities</u> were recognized as items successfully integrated within rural hemophilia care. Furthermore, it was recognized that such needs and capacities were supported by the strengths shared by hemophilia families and health care providers. These needs and capacities were thought to require recognition by the larger health care system in order to provide competent and consistent care for hemophilia families who live in rural communities.

Properties of Thematic Groupings

1. Objective Knowledge

"With a protocol we could be faster and more sure of ourselves."

All participants expressed need for "who, what, when, where and why" of hemophilia care to be clearly and succinctly available in a resource format appropriate for their dynamic setting (i.e. assessment guidelines and treatment protocols). Resource tools specific to rural hemophilia care that adapt and reflect local supports, staff, setting and families were identified as important. Discipline specific basic knowledge requirements were identified as foundational to rural hemophilia care. For example, laboratory technologists indicated a need for a step-by-step protocol on product ordering, dosage, and administration, while nurses expressed need for more breadth and holistic details.

"The in-service [provided by the hemophilia clinic at the rural hospital in 2001] took away the anxiety. [Patients] won't come in here and bleed to death in front of our eyes."

2. Subjective Knowledge

"Without some background information we might not understand the context of their [hemophilia patient care plan]."

Context allows for a complete picture of the patient and family to be evaluated in relation to the objective knowledge. Hemophilia Clinic treatment care plans, travel letters and medical narrative were identified as valuable knowledge. All disciplines identified that subjective knowledge is required alongside objective knowledge to support respectful, safe and effective care delivery.

"There is still a lot of background information that I want to have before I give factor."

3. Roles

"We see a lot of different things coming in off the highway."

All disciplines indicated a respect for the intersecting nature and integrity of multidisciplinary health care provider roles. Scope of practice was identified with a realistic understanding of roles and shared expertise amongst rural providers, Hemophilia Treatment Centre team and families.

"Those [school age] brothers [with severe hemophilia] start their own IV's. I was pretty impressed."

"The family is the expert".

4. Knowing Limits

"We're not doing this all the time. You are and we're not."

All disciplines acknowledged a need for support to do what is required, and a commitment to excellence while recognizing their unique rural context. Rural providers indicated a commitment to competency to adopt protocols or functions that could be realistically and reasonably supported by local resources and capacities. Recognition of inherent rural health care functions and limits elicited an expressed desire for such providers to be recognized as distinct.

"It takes time to ask the questions to get the information that we need. I know I can do it but I don't like to rush and don't want to do it wrong or ruin the product."

5. Trust

"Because we are a team we have a comfort zone with each other, it's a good support. We could see a connection happening. (....) We value that you need to learn to be confident [in hemophilia care]."

Rural providers expressed a need to share control and expertise between health care providers and families. Rural providers expressed admiration for families' ability to manage and treat complex problems and serve as a resource for rural health care providers. Nonetheless, the need was identified for rural providers to have knowledge of their own to support the expertise of families and promote a sense of trust within providers and families alike. It is reasonable to assume that trust is broken down when one link in the larger team systems do not take responsibility for their part. There was a need expressed for sharing control and expertise between health care providers and families. Many rural nurses admired the family abilities to manage, treat complex problems, and maintain a knowledge base that was a resource for nurses and other rural health providers. There was also a need expressed by the rural health providers to have knowledge of their own that supported the expertise of families and increased the trust families had for the team. The rural health providers also wanted to be able to trust their own knowledge.

"The parents are with it [hemophilia] every day. They are reliable. (....) If we don't know what we're doing, confidence in us falters."

6. Teamwork

"Being a rural hospital you deal with things you've never done before. We work together. I think we can do it."

Rural providers indicated working together, solving problems and trust as an important shared workplace approach. Trust is built from strong teamwork, and all members take responsibility for their part. The identified "team" comprised of multidisciplinary rural providers, Hemophilia Treatment Centre staff and families. *"In that big circle we need the family- another important resource. (....) We really rely on our families."*

7. Communication

"The answering machine. That's hard, not to get an immediate answer. We need a human being."

The team approach and shared knowledge were described as facilitators to communication. While communication is an ongoing process and shared responsibility of all team members, coordination of care was viewed as stemming from the Hemophilia Treatment Centre. Such coordination and communication requires a foundational understanding of the rural system, capacities and needs. Rural providers identified that a poor communication may erode hemophilia care provision and trust within the "team".

Telehealth could be used for all sorts of things, from the rural view it is access to specialists. We have folks who have trouble getting to [the city]. It would be nice if they could consult over the TV or phone.

8. Growing Partnerships

"We need to be in the loop."

Growing partnerships is a central theme connecting all of the thematic groupings. Partnerships connect all themes into a cohesive web of meaning and function. The meaning of connections and functions of all team members need to be acknowledged explicitly. When partnerships break down, the meaning of the connections and the function of the various partners are minimized. While existing capacities must be supported, evolving relationships and needs should be supported and nurtured.

"Together build the black and white stuff and then go from there."

Barriers and Facilitators to Hemophilia Care

Responses generated from open-ended focus group discussions indicated various barriers and facilitators related to hemophilia care. Responses reflect areas of hemophilia care related to connecting with the hemophilia clinic (see Table 1) and providing treatment with fractionated blood products (see Table 2). Data reporting was limited to responses provided directly by participants.

Table 1: Connecting with the Hemophilia Clinic - Focus Group

Barriers	Facilitators		
Lack of hemophilia	Hemophilia Clinic program awareness		
resource contact	(communication)		
information			
(communication)			
Inadequate feedback	Networking between rural and		
between rural providers	Hemophilia Clinic care providers		
and Hemophilia Clinic staff	(growing partnerships)		
(communication)			

Table 2: Treatment with Fractionated Products- Focus Group

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Barriers	Facilitators
Inadequate information	Family as immediately accessible
on person with	information resource (growing
hemophilia (<i>subjective</i>	partnerships)
knowledge)	
	Coordination of treatment by Hemophilia
Uncertain role of rural	Clinic (<i>roles</i>)
provider in factor	
concentrate treatment	
(roles)	
	Readily available step-by step ordering
Inadequate information	and administration guidelines (objective
on fractionated products,	knowledge)
access, and	
administration (objective	
knowledge)	

Analysis Considerations

The investigator did not vary from the mediator role during the focus group discussion despite the inherent role as hemophilia nurse clinician; questions relating to hemophilia care and clinical practice were recorded and respectfully deferred until after the focus group discussion (i.e. "we need more information about inhibitors"). There was noted recognition that the investigator's role as hemophilia nurse clinician may hold certain assumptions regarding rural providers' needs and capacities. The investigator addressed such potential bias by putting forth a distinct effort to avoid conjecture and challenge assumptions through open-ended questions; furthermore, the investigator's role as facilitator was reflected upon before and after the sessions with the accompanying research assistant.

At both sites, physicians were paged out of the focus group several times, but soon returned to the discussion. During the focus group discussion, Site 1 participants were awaiting a pivotal hospital budget announcement. Middiscussion, participants were called out to a staff meeting confirming that budget cuts were not anticipated at that time. Despite this disruption, participants offered their comments with similar deliberation *before and after* this announcement. Site 1 had previous hemophilia in-service education and ongoing collaborative coordination of care shared with the HTC nurse, physiotherapist and social worker. Participants appeared comfortable with each other and the research team from the start of the discussion.

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Site 2 had no previous in-service or collaborative care coordination with the HTC. Previous communication was limited to hemophilia clinic summary letters sent to the patient's family physician. Telephone contacts with the HTC were directed to the rural health care provider managing an acute hemophilia bleeding episode. Collaborative care coordination beyond these acute episodes was not undertaken between the HTC and rural site. This was noted by participants, and led to a rich discussion regarding rural provider, HTC and family roles and responsibilities. Participants' discussion initially emphasized problematic patient care specific issues; such issues were noted and deferred for discussion after completion of the focus group. Nonetheless, within five minutes of focus group initiation group participants appeared comfortable in discussion with each other as facilitated by the research team.

Development of Telephone Interview Items

Broad thematic groupings generated from focus group discussions guided question development for the semi-structured telephone interviews. Primary understanding of broad themes marked the first step in creation of survey items. Survey item generation and refinement was recognized as a critical step given the lack of related information in the literature to guide development of such items (Nassar-McMillan & Borders, 2002). As research purpose and questions related to multidisciplinary service, it was fitting to begin this inquiry by seeking the interactive perspective of various rural health care providers by way of focus groups (Hawe, 2001). This fusion of views permitted valuable insight to peer

corroboration in their self-appraisal of needs and capacities related to rural hemophilia care. Furthermore, using the research target population to generate survey items by an inductive approach aptly guided relevance and suitability of such items (Nassar-McMillan & Borders, 2002). From the inductively generated themes additional probing questions for the telephone interview were added.

Stage II- Telephone Interview

Sample

The three sites for semi-structured telephone interviews represented areas to the east, south and west of Calgary situated at 120-minute or greater driving commute to the HTC. Telephone interviews were conducted at each participant's place of employment during regular working hours (Berg, 2001).

- <u>Site 3</u> was located in a community with population over 50,000, with a hospital capacity of over 150 acute care beds and 24-hour emergency service. Residing persons at that time with hemophilia consisted of 5 persons (adults and children) ranging from mild to severe factor VIII (including inhibitor) or IX deficiency. Participants from Site 3 included representation from nursing, social work and laboratory technology.
- <u>Site 4</u> was located in a community with population over 50,000, with a hospital capacity of over 150 acute care beds and 24-hour emergency service. Residing persons with hemophilia consisted of 5 persons (adults and children) ranging from mild to severe factor VIII or IX deficiency.

Participants from Site 4 included representation from physiotherapy, nursing and laboratory technology.

<u>Site 5</u> was located in a community with population of approximately 5,000, with a local hospital capacity of 20 acute care beds and 24-hour emergency service; residing persons with hemophilia consisted of 2 persons (adult and child) ranging from mild to severe factor VIII deficiency. Participants included representation from nursing. The local lab technologist was also recruited, but was unable to participate.

Physicians from all three sites were invited to participate in the telephone interviews by a postal letter (see Appendix D). Physician offices were contacted by telephone to set up an interview time at least twice by the investigator, but office receptionists could not make such an appointment and physicians did not call back. After a stated final attempt to connect by telephone, it was decided to abandon the notion of contacting the physicians as such lack of response was respectfully interpreted as an inability or unwillingness to participate in this research interview.

Themes

Review of telephone interviews and field notes reflected participant comments and comportment holding similar themes to focus group discussions. Furthermore, individual interviews on each of these broad groupings allowed clarification and further reduction of themes. First and second-level coding with saturation of broad thematic groupings were merged and collapsed to 5 main

categories: *objective knowledge, subjective knowledge, communication networks, team roles, and partnerships*. Category properties emerged and were collapsed based on internal consistencies of data sets through "immersion, reflection and crystallization", revealing patterns shared by the multidisciplinary team (Moustakas, 1990). Inclusion properties were redefined throughout the spiraling data analysis process, thereby distilling broad themes to a detailed index of combined distinct and interconnected category sub-themes (Altheide, 1987; Priest, Roberts and Woods, 2002).

New Content within Categories

New terms were noted within the subjective and objective knowledge themes. This included expressed *frustration* of not having the information needed to provide care. This corresponded with previous themes regarding *"objective knowledge*" and *"subjective knowledge*" related to 3 levels of awareness: no program awareness, insufficient program awareness and adequate program awareness. Also, *psychosocial care* of person with hemophilia was introduced and corresponded within existing thematic category of "*subjective knowledge*". *Properties of Thematic Categories*

Category properties from the second research stage were concluded as follows from analysis of telephone interview data:

1. Objective Knowledge:

"We need drugs used, dosages, facts about hemophilia, what to watch for when they come in, quick reference tools, guidelines and protocols. We need specific information about hemophilia care (....) We don't need pages, just basics."

Objective knowledge refers to factual, tangible information, including protocols and practice guidelines, and standards of care. This information was viewed as cornerstone to establishing safe and effective hemophilia care. Furthermore, objective knowledge was recognized as an interconnected, baseline requirement for hemophilia care provision reflected in all other categories.

Hemophilia care is a higher level skill for the [staff]. Need the basics first. (....) When you see the really neat stuff happening with staff moving from figuring it out and anxious, to taking over and being confident and moving to expertise.

"Staff awareness (...) of [hemophilia] treatment, diagnosis and any deviation from the norm make the family draw comfort and confidence as well."

2. Subjective Knowledge:

"The actual care plan starts with the basics of hemophilia care and objectives of assessment. Then as the staff get to know the parents they start to fine tune the care plan for the child and the parent."

Such contextual, individual information was identified as an extension of objective knowledge, thus completing the holistic picture of patient and family. This information is viewed essential for safe and effective care given each hemophilia family's particular responses to bleeding episodes and treatment.

"See how [hemophilia families] can function in their normal lives. Keep in mind the underlying experience. We see the needs and do our best to follow them."

3. Communication Network:

"People feel better knowing how to access resources. (....) Awareness of who is on the hemophilia team, what they do and how to get a hold of them. Who can answer the questions we have."

Facilitated by an established set of connections, information transmission and feedback was viewed to be multidirectional amongst all team members. Persons, information transfer processes, and technology are recognized as important facets in this system.

"We want to talk with hemophilia staff. Nurse, doctor or physiotherapist, whoever is most familiar with the person and the problem and what precautions to be made aware of, and to make sure that the bleeding is under control."

4. Team Roles:

"Our (staff) take care of many patients at once. (....) Hemophilia just happens in this larger picture. This needs to be respected about what we can do and what we are faced with."

Hemophilia team roles were identified as having both group and individual purpose and responsibility. Such collaboration is required related to the overlapping nature of multidisciplinary family centered care. Recognition of realistic abilities further defined the scope of practice in specialty hemophilia

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care. The "team" was recognized as comprising of rural health care providers, specialty clinic providers and the hemophilia family.

"We need to know what has to happen."

[Staff] need to know what the parents know. They need to be as informed as the parents. When we don't know these things it causes discomfort and difficulty with staff, and with the family it can be a bit of a problem. Not fair to the family and confusing to the staff too. Some of those little things cause confusion. This can put up barriers especially when [families] are drawing from their experience at the [hemophilia clinic] then when they come to a more general unit they have some preconceived notion that this is not as good care. Sometimes we use a different solution than at the specialty clinic but we have our rationale. We are still competent but different.

5. Partnerships:

I like how it is all handled [care coordination] through the hemophilia clinic. This helps since we do not have too many families with this. (....) The hemophilia clinic is like the hub of the wheel with the spokes going out to everyone involved.

Partnerships were defined as a formal alliance, founded and sustained by shared expertise, connection, accountability, trust, and team work. While objective knowledge was recognized as cornerstone to hemophilia care, the central theme of partnerships was viewed as connecting all categories as a cohesive web of meaning and function.

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"It's not a quick fix – it comes as a whole package."

Barriers and Facilitators in Hemophilia Care

Responses generated from semi-structured telephone interview questions indicated various barriers and facilitators related to hemophilia care. Responses reflect areas of hemophilia care related to connecting with the hemophilia clinic (see Table 3) and providing treatment with fractionated blood products (see Table 4). Data reporting is limited to responses provided directly by participants.

Barriers	Facilitators			
Voice mail	Fax (communication)			
(communication)				
	Telephone and pagers(communication)			
	e-mail (communication)			
	Receptionist (communication)			
	Emergency contact information (communication)			
	Emergency contact mormation (commanication)			
	Telehealth & videoconferencing (communication)			
	3 (
	Collaborative care planning with rural and			
Overall lack of	hemophilia staff			
awareness of	(partnerships)			
hemophilia				
program	Routine hemophilia information bulletins to rural			
(roles)	providers (communication)			

Table 3:	Connecting	with the	Hemophilia	Clinic
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Table 4: Treatment with Fractionated Product

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Barriers	Facilitators
Inadequate succinct	Updated and accessible institutional
information on hemophilia	policies and procedures for transfusion
(objective knowledge)	(objective knowledge)
Inadequate information on	Step by step protocols for general
fractionated products, access	hemophilia and individual patient care
availability and administration	(objective knowledge)
(objective knowledge)	
(objective knowledge)	Readily accessible information on
Infraguant avpariance with	fractionated products and administration
factor proportion and	including stock requirements (ship stick)
actor preparation and	Including stock requirements (objective
administration (objective	knowledge)
knowledge)	
	Patient treatment information (subjective
Caring for patients who are	knowledge)
not registered with hemophilia	
clinic(subjective knowledge)	Readily accessible hemophilia clinic
	contact information and resources
Rural and hemophilia clinic	(communication)
guidelines for factor	
administration that do not	Rural staff with related experience
match (partnerships)	(teamwork roles)
	Coordination of treatment by hemophilia
	clinic (teamwork roles)
	Clarity of team roles and responsibilities
	(teamwork roles)

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Analysis Considerations

As in the focus group discussion, a distinction was noted in participants who shared collaborative care planning and educational programming with the HTC. This group of participants expressed greater confidence in providing hemophilia care. Reflexivity was noted throughout the research process, with recognition that the student investigator's role as hemophilia nurse clinician may assume certain responses. The student investigator addressed such potential bias by putting forth a distinct effort to avoid conjecture and challenge assumptions through open-ended questions; furthermore, the investigator's role as facilitator was reflected upon before and after the sessions with the fellow research investigators.

Development of Survey

First and second-level themes adequately addressed the study purpose to support a mixed-method, successive process in survey development; deeper construct exploration was not undertaken as these qualitative research stages were not intended to generate theory or concept analysis (Priest, Roberts and Woods, 2002). Telephone interviews were appropriate for this stage of research as this permitted further exploration of generated themes and access to wider geographical area for participant recruitment (Berg, 2001). Exploration of themes from this wide geographical perspective captured similarities and variations unique to different locales; this was required to inform development of relevant and suitable survey items.

Stage III- Mail-out Survey

Sample

All rural communities (n=11) served by the Calgary Health Region Hemophilia Clinic were represented in this sample of 56 multidisciplinary providers, and all targeted disciplines were recruited for this study. Response rate was 48% (n=31; N=64) from the convenience sample; the added snowball sample for those rural providers not individually identified yielded a response rate of only 18% (n=25; N=136). Almost all respondents indicated the rural hospital as their main place of work (92.8%; n=52). Sample consisted primarily of veteran multidisciplinary providers, with 89.3% (n=50) reporting greater than 10 years experience in their field (see Table 5). The demographic profile of the recruited sample of nurses, physicians, pharmacists and physiotherapists was comparable to the ratio of healthcare providers in the Canadian healthcare system (Canadian Institute for Health Information, 2000).

Over 82% of respondents indicated experience in urgent hemophilia management (see Table 6). However, only 58.9% (n= 33) total sample reported urgent hemophilia care practice within the past 12 months. Furthermore, the variety of experiences was also limited as respondents indicated care provision for an average 1.7 distinct individuals with hemophilia. As nursing (n=38) provided the majority of responses, lab technologists, physicians, pharmacists and physiotherapists were grouped and identified as *allied health* (n=18) for comparative purposes in the remainder of reporting.

Table 5: Demographic Profile of Survey Respondents

Occupation	Respondents	Highest Level of Education
	% (n)	(n)
Registered Nurse	67.9% (38)	College diploma (26)
		University undergraduate or
		higher (12)
Lab Technologist	19.6% (11)	College diploma (7)
	,	University undergraduate or
		higher (11)
Physician	7.1% (4)	University undergraduate or
		higher (all)
Pharmacist	3.6% (2)	University undergraduate or
		higher (all)
Physiotherapist	1.8% (1)	University undergraduate or
		higher (all)
TOTAL	100% (56)	

Table 6: Hemophilia Experience of Survey Respondents

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Experience	Average Hemophilia Care Hours
	within past 12 months
Registered Nurses	23.7%(9)= no hours
with urgent hemophilia care experience 92.1% (35)	50.0% (19) = 1-5 hr
	10.7% (1) = 6-15 hr
	~ ~ ~
	not indicated 23.7% (9)
Allied Health	44.4% (8) = 1-5 hr
with urgent hemophilia care experience	
61.1% (11)	27.7% (5) = 6-15 hr
	not indicated 27.7% (5)

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Results

Part One –Comparison on the Importance of Learning and Resource Categories for Rural Hemophilia Care

Responses between nurses and allied health were compared regarding the importance of survey item ratings within each of the 5 main categories: objective knowledge, subjective knowledge, communication, team roles and partnerships. High ratings were interpreted as responses on a 5-point Likert scale corresponding to important (score of 4) and most important (score of 5). Survey items with high ratings were compared between nurses and allied health to identify perceived priorities of learning and resource items. Means of items related to learning needs and capacities were compared across groups using 2-tailed t-tests (see Table 7) and Spearman's correlation; comparison with non-parametric testing by contingency table revealed similar findings.

Nurses rated objective knowledge, subjective knowledge and partnership items as having statistically significant higher importance when compared with other health colleagues. Nonetheless, both groups rated the objective knowledge category with overall top importance. High correlations (r = .737) were also noted between nurses and other care providers in their ratings of communication items related to hemophilia care.

Table 7: Importance of Learning and Resource Categories for Rural Hemophilia Care

Looming or d	Numero		0
Learning and	Nurses	Allied Health	Significant
Resource	n=38	n=18	Differences
Needs and			Between
Capacities:			Groups
5 Categorical			bv
Themes			t-test
Objective			
Knowledge	M = 85.87	M = 77.77	*p = 0.005
19 survev items	SD =11.37	SD= 16.46	SD = 10.99
	(rank#1 of 5)	(rank#1 of 5)	00 10.00
		(10111111010)	
Subjective			
Knowledge	M = 81.25	M = 68.04	*p = 0.005
8 survey items	SD = 11.21	SD = 18.46	SD = 9.28
	(rank #2 of 5)	(rank #2 of 5)	
Communication			
Network	M = 65.49	M = 67.91	p = 0.467
18 survey items	SD = 20.28	SD = 13.54	SD = 13.78
	(rank # 4 of 5)	(rank #3 of 5)	00 10.70
Team Roles	(
13 survev items	M = 72.47	M = 64.55	p=0.072
	SD = 11.08	SD=10.51	SD= 14 49
	(rank #3 of 5)	(rank #4 of 5)	00-14.40
Partnershins			
11 cuniou itoms	M - 60 36	M - 58 08	*n = 0.004
I I SUIVEY ILEIIIS		101 - 30.00	p = 0.004
	5D = 15.22	5U = 17.82	0 = 9.91
	(rank #5 of 5)	(rank #5 of 5)	

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Part Two- Comparison between Groups of Important Learning and Resource Items for Rural Hemophilia Care

Responses of nurses and allied health care providers were compared to determine the relationship of highly rated individual survey items (N=69) between groups within each of the 5 main categories. Means of Likert scale items were compared within each of the 5 main categories and further analyzed by 2-tailed t-test; comparison with non-parametric testing by contingency table results revealed similar findings. Differences (see Table 8) and correlations (see Table 9) were noted between groups with regard to rated importance of learning and resource needs.

In analysis of each of the five categories as aggregates, differences between groups were noted to be statistically significant, with nurses providing higher ratings of such individual items. However, some individual items within categories were noted to have significant correlations. Within the *objective knowledge* category, nurses and allied health providers' ranking of the "treatment guidelines" item was significantly correlated (r=.965), with a high importance rating in over 90% of responses. Respectively within the *communication network* team role categories, "peer to peer communication links" and "awareness of multidisciplinary practice" items also revealed significant correlation, noting a high importance rating in less than 70% of responses.

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Table 8: Importan	t Learning and I	Resource Items for Rural	Hemophilia
Care: Di	ifferences		-
Learning and	Items rated	Frequency of High	Difference

Learning and Resource Needs and Capacities	Items rated with High Importance	Frequency of High Ratings for each item	Difference Between Groups by t-test
Objective Knowledge	Assessment Guidelines	Nurses 94.7% (36) Allied Health61.1% (11)	*p =. 001
19 survey items	Triage Guidelines	Nurses 81.6% (31) Allied Health 50% (9)	*p =. 015
Subjective Knowledge 8 <i>survey items</i>	Patient Information on Permanent Chart	Nurses 73.7% (28) Allied Health 44.4% (8)	* <i>p</i> =.033
Communication Network 18 survey items	Medic Alert	Nurses 81.6% (31) Allied Health 55.6% (10)	*p=0.04
Team Roles 13 survey items	Family's skill in hemophilia care	Nurses 92.1% (35) Allied Health 72.2% (13)	* <i>p</i> =0.047
	Basic Patient Teaching Guidelines	Nurses 84.2%(32) Allied Health 55.6% (10)	* <i>p</i> =0.021
Partnerships <i>11 survey items</i>	Family's knowledge of hemophilia	Nurses 89.5% (34) Allied Health 61.1% (11)	* <i>p</i> =0.013

 Table 9: Important Learning and Resource Items for Rural Hemophilia

 Care: Correlation

Learning and Resource Needs and Capacities Themes	Items rated with High Importance	Frequency of High Ratings for each item	Spearman's Correlation Between Groups
Objective Knowledge 19 survey items	Treatment Guidelines	Nurses 94.7%(36) Allied Health 94.4% (17)	*r = .965
Communication Network 18 survey items	Peer to Peer Communication Link	Nurses 65.8%(25) Allied Health 66.7%(12)	*r = .95
Team Roles 13 survey items	Multidisciplinary Scope of Practice	Nurses 65.8% (25) Allied Health 66.7% (12)	*r = .95

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Part Three – Categories Rated with High Importance and Practice Application

Responses of nurses and allied health were noted to determine the relationship of highly rated individual survey items and application to current practice in hemophilia care. Survey items with *high ratings* were analyzed as an aggregate within each category. Practice application was noted by identifying the frequency of responses indicating the survey item as part of current practice. Statistically significant differences are interpreted as *needs* by reflecting gaps in items rated as important with application to practice (see Table 10); comparison with non-parametric testing by Wilcoxon-Signed Rank revealed similar findings.

Findings indicate that although learning and resource categories were highly rated overall by the majority of providers, there is a noteworthy gap in related application to practice. This was found to be statistically significant in all categories for both groups, with one exception in the allied health group related to the importance and current application of partnership related themes in practice. While allied health did not report a significant discrepancy in their ratings of partnership items, this category also had the lowest ascribed value with an overall average of only 58% high importance rating.

 Table 10: Learning and Resource Needs as indicated by Practice

 Application

Learning and Resource Needs and Capacities Themes 69 <i>survey items</i>	Nurses Comparison of High Importance with Current Practice by 2-tailed t-test	Allied Health Comparison of High Importance with Current Practice by 2-tailed t-test	Learning or Resource Need
Objective Knowledge 19 survey items	M =85.87; 32.37 ** <i>p</i> <0.000 SD = 20.06	M =77.77; 33.05 * <i>p</i> =0.000 SD =28.14	Yes – both nurses and allied health
Subjective Knowledge 8 <i>survey items</i>	M =81.25 ; 31.76 * <i>p</i> <0.001 SD= 14.11	M = 68.04; 26.26 * <i>p</i> =0.001 SD =20.63	Yes – both nurses and allied health
Communication Network 18 survey items	M =65.49; 23.06 * <i>p</i> <0.001 SD=25.75	M = 67.91; 33.76 * <i>p</i> =0.000 SD= 32.70	Yes – both nurses and allied health
Team Roles 13 survey items	M =72.47; 33.35 * <i>p</i> =0.001 SD= 18.945	M = 64.54; 41.31 * <i>p</i> =0.001 SD= 19.7	Yes –both nurses and allied health
Partnerships <i>11 survey items</i>	M = 69.36; 24.53 * <i>p</i> <0.001 SD= 18.428	M = 58.08; 41.64 <i>p</i> =0.154 SD= 35.35	Yes- nurses

Barriers and Facilitators to Hemophilia Care

Responses generated from open and closed-ended survey questions combined have indicated various barriers and facilitators to rural hemophilia care. Responses reflect areas of hemophilia care related to connecting with the hemophilia clinic (see Table 11) and providing treatment with fractionated blood products (see Table 12). Data reporting is limited to responses provided directly by participants.

Barriers and facilitators to connecting with the hemophilia clinic were most often related to resource elements found in the communication category. However, barriers and facilitators to treatment with fractionated product reflect all five key learning and resource needs and capacities related to objective knowledge, subjective knowledge, communication network, team roles and partnerships.

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Table 11: Barriers a	nd Facilitators	to Connecting	with the	Hemophilia	Clinic
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Barriers	Facilitators
Lack of readily available	Readily available Hemophilia Treatment
information on hemophilia	Centre contact information
program (<i>partnerships</i>)	(communication)
Lack of awareness	Awareness of Hemophilia Treatment
regarding communication	Center program and services (teamwork
inks with nemophila clinic	roles)
stan (communication)	Peer to peer link (communication)
Voice mail	
(communication)	Telephone & pager access
((communication)
	Live receptionist (communication)

Table 12: Barriers and	Facilitators to	Treatment with	Fractionated	Blood
Products				

Barriers	Facilitators
Required information not	Step-by-step factor ordering guidelines
readily available to all providers (partnerships)	(objective knowledge)
providoro (pararorompo)	Step-by-step factor administration guidelines(objective knowledge)
Uncortain product	Treatment indications (objective knowledge)
availability <i>(teamwork</i>	Treatment rationale (objective knowledge)
	Basic hemophilia knowledge <i>(objective knowledge)</i>
	Hemophilia clinic individualized care plan (<i>subjective knowledge</i>)
	Fractionated product availability (<i>objective knowledge</i>)
Lack of awareness of	Communication link with hemophilia clinic (communication)
related resources (communication)	After hours link with hemophilia clinic (communication)

Learning and Resource Supports

Throughout the study, participants indicated that a multidisciplinary education session would be desirable. Survey respondents were asked to identify the education program method that would best support their needs and capacities (see Table 13). This was identified in a check-list of closed and open survey items. Furthermore, preferred education session presenters were also identified.

Other related educational preferences identified included information packages, annual updates and recommendation to provide shorter education sessions to ensure better attendance. Preferred speakers beyond those identified as top priority included presentations (respectively) by Transfusion Medicine, Canadian Hemophilia Society, Canadian Blood Services, Social Work, Pharmacy, Rural Health Providers (i.e. nurse and physician) and Physiotherapy. No other preferred education session speakers were identified.

Day	
Educational Session Format by	Presenters by
Rank	Rank
1 st	1 st
1-2 hour hemophilia educational in-service at rural hospital	Hemophilia Nurse Clinician
2 nd	2 nd
1-2 hour hemophilia educational in- service by telehealth	Hemophilia Hematologist
3 rd	3 rd
Multidisciplinary education day at Hemophilia Clinic site	Person with Hemophilia

Table 13: Ranking of Preferred Supports for a Multidisciplinary Education Day

Research Findings Summary

The five main categorical themes (objective knowledge, subjective knowledge, communication, teamwork roles, and partnerships) were noted in all three research stages. While objective knowledge (i.e. treatment guidelines) was defined as the basic prerequisite, *partnerships* (i.e. collaboration of providers and families) were essential to establishing shared meaning for all those involved in the continuum of care. While the closed-ended survey confirmed themes. nurses rated most items with greater importance as compared with allied health colleagues. Resource needs in rural hemophilia care were identified by gaps between high item ratings and application to practice: all themes revealed statistically significant needs. Supports specific to hemophilia related educational needs ranked top preferences as hemophilia in-services at the local rural hospital and telehealth sessions; the top ranked presenters at such educational events included hemophilia nurses, hematologists and families. These findings require consideration with regard to subsequent clinical, theoretical and research implications.

CHAPTER FIVE

DISCUSSION

Research Questions Answered: Practice Implications

Research Question #1: What are the learning and resource needs and capacities of rural hemophilia health care providers?

Qualitative Summary:

Qualitative analysis of themes first revealed the needs and capacities of rural hemophilia providers. Needs were interpreted as items that are not being met while capacities were recognized as items successfully integrated within rural hemophilia care. Capacities were also viewed as needs that had been adequately supported; needs and capacities require the supportive strengths of hemophilia families and health care providers. Recognition of needs and capacities assisted with the identification of supports required for competent and consistent care for hemophilia families who live in rural communities. Content analysis of recurrent patterns and processes in interview and field notes yielded 5 main themes: *objective knowledge, subjective knowledge,*

communication network, team roles, and partnerships. These themes revealed requirements for supporting multidisciplinary providers in safe and effective rural hemophilia care as follows:

1. **Objective Knowledge** including succinct information resources such as protocols, practice guidelines and standards of care was identified

as a baseline requirement for safe and effective hemophilia care provision.

- 2. *Subjective Knowledge* including contextual, individual care plan information extending objective knowledge was identified as a requirement for rural provider provision of holistic care of the patient and family as persons.
- 3. **Communication Network** including formal connections shared by persons, processes and technology was identified as a requirement to facilitate multi-directional information transmission and feedback amongst the collaborative care team: rural providers, tertiary clinic staff and hemophilia families.
- 4. *Team Roles* within the overlapping nature of multidisciplinary familycentered care was noted as a requirement to identification of team responsibilities, scope of practice and shared trust for the competent provision of specialty hemophilia care.
- 5. *Partnerships* founded and sustained by shared expertise, affiliation, accountability, and trust were identified as a central requirement to connecting all categories as a cohesive web of meaning and function in collaborative rural hemophilia care.

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Inductively generated data provided by focus group and telephone interview participants permitted a broad view of this research problem, while revealing the converging needs and capacities of multidisciplinary rural providers. The notion

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of enhanced collaboration through role clarity is similar to findings reported by Minore and Boone (2002) in their research on remote Canadian multidisciplinary teams. The research approach allowed for survey items to be generated by rural hemophilia providers themselves, thus providing greater relevance and suitability of the mail-out survey.

Quantitative Summary

Quantification of qualitatively generated survey items permitted "confirmation" (Breitmayer, Ayres & Knafl, 1993, p. 238) of learning and resource needs and capacities of rural hemophilia health care providers. While the initial purpose of method triangulation was to inform survey design, qualitative and quantitative analyses were mutually confirmed by way of their similarities. Core themes were confirmed by the continued high overall survey ratings of all 5 categories. However, dimensions within these categories had varying ratings of importance. Therefore it is recommended that future multi-method inquiry explore the "completeness" (Breitmayer, Ayres & Knafl, 1993, p. 238) of such dimensions within learning and resource needs and capacities.

Study findings suggest the following recommendations for multidisciplinary practice to promote improved awareness and application of learning and resources required in rural hemophilia collaborative care:

 Provide explicit information of the 5 key elements required for rural hemophilia care resources: objective knowledge, subjective knowledge, communication network, team roles, and partnerships.

- 2. When creating resources to address objective knowledge needs, include information pertaining to hemophilia basic information and pathophysiology, pain management, guidelines (triage, assessment, and treatment) typical and atypical responses to treatment, secondary problems related to hemophilia, bleeding risk factors and prevention strategies. This information should be readily available to providers (i.e. general hemophilia information file in patient care unit).
- 3. When creating resources to address *subjective knowledge* needs, include information pertaining to *individual health status and hemophilia care plan, usual response to treatment.* This information should be readily available to providers (i.e. patient binder in emergency).
- 4. When creating resources to address *communication* network awareness needs, include information pertaining to *hemophilia clinic and emergency after-hours contact lists (including pager and telephone numbers) and salient information on hemophilia program services.* This information should be readily available to providers (i.e. contact list posted in department).
- 5. When creating resources to address *team roles* awareness needs, include information pertaining to *family's skill in hemophilia care, and care guidelines that aptly reflect the scope of practice of rural and hemophilia clinic providers.* While such allocation and delegation of responsibilities may be initially led by the hemophilia clinic, this ongoing function is

recognized to highly contextual, and therefore recognized to be a dynamic responsibility shared by all partners.

- 6. When creating resources to address *partnerships* awareness needs, include information pertaining to *family's knowledge of hemophilia, local supports, and hemophilia clinic resources.* This information must be explicitly shared amongst all partners regarding the individualized plan of care. While such networking may be led by the hemophilia clinic, this ongoing function is highly contextual, and therefore recognized to be a dynamic responsibility shared by all partners.
- 7. Establish routine hemophilia information dissemination and feedback loops shared with all members of the collaborative care team. *This may include hemophilia bulletins, team meetings, case management discussions and education sessions.*
- 8. Support the formal connection of rural hemophilia providers from other communities as a unique resource and support. *This may include facilitation of linkages between other rural hospitals with a residing hemophilia family.*

It is recommended that above solutions be considered as possible interventions to support the learning and resource needs of rural hemophilia health care providers.

Research Question #2: What do rural hemophilia health care providers identify as barriers and facilitators regarding linking with the Hemophilia Treatment Center comprehensive care team as a resource?

Barriers and facilitators were identified through focus groups, telephone interviews and surveys. Barriers were interpreted as an obstacle in hemophilia care that impeded the availability of learning and resources required for connecting with the hemophilia clinic. Facilitators were interpreted as strengths in hemophilia care that assisted with the availability and implementation of learning and resources required for connecting with the hemophilia clinic. Survey questions reflect facets related to thematic categories related to communication networks and team roles.

It is recommended that identified barriers and facilitators to connecting with the hemophilia clinic be considered when providing collaborative care with hemophilia families in rural settings. All members of the collaborative care team are recognized for their role in reducing barriers and facilitating strengths related to rural hemophilia care. The hemophilia clinic is well suited to provide primary transition coordination of communication links required for rural care, given the inherent expertise related to hemophilia care needs. Within the collaborative care team itself, it is recommended that multidisciplinary contacts be established to ensure seamless service delivery beyond the urban centre. This may be possible with promotion of the following:

- Accountable, collaborative partnerships shared amongst all team members in family-centred hemophilia care;
- Readily available, explicit information on hemophilia program services and resources such as transfusion medicine and Canadian Blood Services;
- Explicit awareness of roles and responsibilities of rural providers, hemophilia clinic staff and families; and
- Routine multidisciplinary hemophilia meetings for case management, education and team building at the rural center or through distance delivery by teleconference.

Resources to support hemophilia clinic communication links should include information on the following:

- Readily available Hemophilia Treatment Centre contact information (including emergency and after hours);
- Mutually effective communication options (including fax, telephone, e-mail and telehealth)
- Peer to peer links;
- Telephone & pager access (including immediate assistance when voice mail is not appropriate); and
- Connection with live receptionist at hemophilia clinic/ tertiary care centre.

Research Question #3: What do rural hemophilia health care providers identify as barriers and facilitators regarding treatment with fractionated blood products?

Barriers and facilitators were identified through focus groups, telephone interviews and surveys. Barriers were interpreted as an obstacle in hemophilia care that impeded the availability of learning and resources required to prepare rural providers for treatment with fractionated blood products. Facilitators were interpreted as strengths in hemophilia care that assisted with the availability and implementation of learning and resources required to prepare rural providers for treatment with fractionated blood products. Survey questions reflected facets combining all 5 thematic categories: *objective knowledge, subjective knowledge, communication networks, team roles, and partnerships.*

It is recommended that identified barriers and facilitators to treatment with fractionated product be considered when providing collaborative care with hemophilia families in rural settings. All members of the collaborative care team are recognized for their role in reducing barriers and facilitating strengths related to rural hemophilia care. The hemophilia clinic is well suited to provide primary transition coordination of fractionated blood products for rural care, given the specialty area expertise and supporting budget to provide outreach beyond the tertiary care centre: provincial health funding to the Calgary Health Region has allocated approximately 20% for outreach services (Calgary Health Region, 2001). Within the collaborative care team itself, it is recommended that multidisciplinary contacts be established to ensure seamless service delivery beyond the urban centre. This may be possible with promotion of the following:

- Accountable, collaborative partnerships in family-centred hemophilia care;
- Readily available, explicit information on hemophilia program services and resources such as transfusion medicine and Canadian Blood Services;
- Explicit awareness of roles and responsibilities of rural providers, hemophilia clinic staff and families;
- Routine multidisciplinary hemophilia meetings for case management, education and team building at the rural center or through distance delivery by teleconference (including certification program on treatment with fractionated products); and
- Registration of all hemophilia patients with the hemophilia clinic.

Resources to support rural treatment with fractionated products should include information on the following:

- Corresponding institutional treatment guidelines for fractionated products;
- Step-by-step fractionated product ordering and administration guidelines (including stock requirements);
- Treatment indications and rationale;
- Succinct, basic hemophilia knowledge;
- Hemophilia clinic individualized care plan;
- Fractionated product availability; and
- Communication link with hemophilia clinic (including after hours).

Study Limitations

In the focus group stage of research, limitations were noted as the data collected emphasized the verbal responses of participants, and thereby did not fully capture the context of the situation. It would be a worthwhile consideration to include greater observational detail on the expressions and behaviours between and within individual participants (Carey & Smith, 1994). While there was an inherent difficulty noted to capture nuances within the focus group process, recorded field notes on participant context were invaluable in the interpretation of collected data.

In the focus group and telephone interview stages of research, a potential limitation was noted in the relationship between the investigator and participants given the dual role held by the investigator as interviewer *and* hemophilia nurse clinician. The investigator worked with these same rural providers to coordinate care for hemophilia patients in the study catchment area. As participants were involved in rural hemophilia care collaboration with the investigator, potential response bias cannot be excluded. Nonetheless, investigator consistency was appraised as necessary in having a constant person with hemophilia-related expertise to function as focus group facilitator and telephone interviewer. Furthermore, the investigator's required hemophilia nurse coordinators in Canada; thus, employing a suitable interviewer without connection to rural hemophilia care was not a feasible consideration.

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In the survey stage of research, limitations were noted in the use of convenience sampling. Allied health was represented in mail-out surveys by a small number from each profession; however, this was representative of the staff mix from such rural institutions. Furthermore, while all sites responded to the survey, the distribution of responses was not even. Several sites made up less than 5% of the sample size or had only 15% response rate from their area from the purposive sample list. While the focus groups and telephone interview participants were recruited as planned, the mail-out survey had lower than expected response rate. Therefore, it is recognized that these findings cannot be widely generalized beyond this limited group of participants. Results are presented with the understanding that this area of study is emerging and requires further exploration. Moreover, generalizability to other settings was not appropriate, as intent was to uncover area-specific needs.

Clinical Implications

Application of Findings to Education Day Development

As the notion of an education in-service was an indicated resource preference by study participants in all stages of the research process, an educational session was implemented to clinical practice by member of the Southern Alberta Hemophilia Clinic. The Hemophilia Clinic comprehensive care team tailored education day presentations (see Appendix K) based on the preferred format and content identified by survey participants. The one day, multidisciplinary program development was based on rural provider identified needs and capacities.

Furthermore, the program was offered on the rural provider preferred date, timeframe and mixed method of on-site and telehealth delivery. While providers identified their first preference to partake in an onsite in-service delivered by multidisciplinary hemophilia providers, this option was not feasible given staff resource limitations.

As previously indicated development of the educational program was guided by rural providers' expressed needs and capacities and augmented with expertise shared by the hemophilia comprehensive care team. This multidisciplinary program began with a foundation of *objective knowledge* elements, with teaching on hemophilia basics and emergency care. This led to progressive building of content related to *subjective knowledge, communication and team roles.* Dimensions of *partnerships* were interwoven throughout presentations and informal gatherings related to this event. As this was essentially an outcome of the study, and not part of the study per se, the summary and evaluation are appended (see Appendix J, K, L, & M).

Theoretical Implications

Partnerships were seen as the central theme connecting meaning within all categories. The collaborative partnership was recognized to comprise all team members including rural care providers, specialty clinic staff and hemophilia families. While all team members were recognized for their inextricable link to each other in this system, inherent roles and responsibilities also required explicit, shared understanding by all. However, these roles were noted to be

dynamic based on the context of each situation and transitions experienced over time (Meleis et al., 2000). Therefore, it is recommended that needs, roles and responsibilities may be better understood and applied by adapting a multidisciplinary care model that also reflects and supports the family as an integral partner in care provision.

Health in rural areas may be promoted through dynamic, collaborative partnerships such as networks and alliances (Bushy, 2000). Partnerships may be organized from several theoretical framework perspectives. Social support theory describes partnership networks as an exchange of information, goods, services and problem solving (MacElveen, 1978; Goeppingen, 1993). Development of partnership interactions and linkages through informal structures leads to meaningful, collaborative action (Goeppingen, 1993). Within rural care, this notion of social support and collaboration is inherent as health provision is often team driven related to overlapping resources (Bushy, 2000).

Education and learning was appraised to be cornerstone to competent health care delivery, and subsequently required for continuous quality improvement and teamwork. Health providers indicated a need for information related to problem solving, teamwork, communication, partnerships and accountability; this common knowledge base should be supported by an inclusive learning process (Raether, 1997). Standards, goals, philosophy, roles and communication systems should also be commonly understood (Bulau, 1997). Furthermore a need to integrate such workplace knowledge with family-centred, collaborative partnership

approaches has been recognized (Raether, 1997; Institute for Family-Centered Care, 2003).

Integration of a family-centred partnership approach is posited to enhance transformative growth associated with transitions (Meleis et al., 2000). Transition phenomena are induced from critical experiences with illness and health. developmental changes, and organizational, situational and environmental factors (Qualls, 1997; Meleis & Trangenstein, 1994). Within the evolving health and illness experiences of the hemophilia family there is an ongoing, dynamic requirement for the continuing competency of health care providers as partners in family-centred care. Moreover, transition experiences may be facilitated by multidisciplinary rural care professionals who have adequate preparation and resources for the provision of safe and effective hemophilia care. It is recommended that the adequate preparation of rural providers in specialty care be considered foundational to family-centred partnerships and transition-induced transformative growth: an opportunity for rural and tertiary providers to work together with families to enhance wellness and diminish vulnerability (Meleis et al., 2000).

As previously described in Chapter 2, Oberle and Davies' (1993) "Supportive Care Model" effectively represented this collaborative care partnership. The Supportive Care Model explicitly illustrated application of six interconnected and fluxing care dimensions from a family-centred perspective: "valuing, connecting, empowering, doing for, finding meaning and preserving integrity" (p. 68). It is

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recommended that further inquiry and evaluation be done regarding application of the Supportive Care Model to assist in the systematic identification of roles, responsibilities, and dynamic needs in hemophilia care partners. Identification of such facets will assist in the recognition and support of foundational learning and resource needs and capacities for all partners involved in rural hemophilia care: tertiary and rural providers and families are recognized to be partners in hemophilia care.

Research Implications

Multidisciplinary hemophilia health care providers are encouraged to extend this research through critical appraisal of intersectoral, family-centred collaborative partnerships (Canadian Nurses Association, 2002). While this study has served to inform hemophilia care, further research is required to explore emerging qualitative themes and clarify findings beyond this studied sample. Barriers and facilitators related to implementation of the 5 key learning and resource elements (objective knowledge, subjective knowledge, communication networks, team roles and partnerships) require further evaluation. Additional investigation is needed on the barriers and facilitators particular to collaborative partnerships as shared amongst rural providers, specialty clinic staff and hemophilia families, as such understanding will assist in upholding effective shared supports for hemophilia care. Furthermore, replication of any or all of these research stages will assist with clarifying the learning and resource needs and capacities of rural hemophilia health care providers beyond the sample recruited. Nonetheless, several respondents indicated that the mail-out survey was drawn out and bulky; therefore abbreviation should be considered for future application.

Future research directed towards evaluating the application of findings generated in this study may include impact of source-identified learning needs implementation for rural hemophilia health care providers. Furthermore, the converging learning needs and capacities of rural providers, tertiary specialty clinic team and hemophilia families are also worthy of further examination given the collaborative partnership theme emerging from this data. Research by Parker and colleagues (2002) points to the successful development and implementation of a rural resource manual for specialty cardiac care through converging input provided by focus groups and surveys of providers and families. Future research in this area is required to establish best practice guidelines for rural providers (Jensen & Royeen, 2002). Such guidelines are required to support safe and effective care of hemophilia families irrespective of their distance to the specialty clinic. Of interest, this research topic reflects national healthcare research priorities as indicated by the Canadian Institute of Health Research (1998) and the Child and Youth Homecare Network (2003).

Conclusion

Accountable partnerships shared by the specialty tertiary clinic, rural hospital and family may be facilitated by providing rural hemophilia providers with effective resources. While there is an accumulation of educational materials available for hemophilia providers, findings from this study suggest that such information needs to be readily available while also addressing 5 key elements: objective knowledge, subjective knowledge, communication, team roles and partnerships. Each discipline has particular resource needs, capacities and responsibilities that aptly reflect scope of practice. However, such delineation is extended and connected within the larger web supporting safe and effective care. Moreover, strengthening of collaborative partnerships is thought to facilitate awareness of hemophilia care needs and supports, thus assisting with provision and uptake of user-friendly resources. As formal evaluation of learning resources developed from the rural hemophilia providers' perspective needs has not been identified, further investigation is recommended to evaluate the impact of such continuing education. While individuals have varying resource requirements to prepare for hemophilia care, needs recognition and capacity strengthening is a shared responsibility of all collaborative care partnership members.

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Focus Group Recruitment Poster

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WE NEED YOU! INVITATION TO PARTICIPATE IN A FOCUS GROUP

What is it about?

As part of a University of Calgary, Faculty of Nursing research project we are conducting a focus group in your hospital to explore the unique <u>learning and</u> resource needs and capacities (strengths) of rural hemophilia health care

providers.

Why should I participate?

Your participation is important, as information gathered in this discussion will be used to develop supports for learning and resources in your area, such as a oneday workshop for multidisciplinary rural hemophilia health care providers.

Who can participate?

The focus group is open to a maximum of 12 participants:

*registered nurses, *physicians, *social workers, * physiotherapists, and

*lab technicians & *pharmacists who manage fractionated blood products.

What about confidentiality?

All comments made in the focus group will remain confidential.

When, where and how?

Date: Friday September 27th, 2002

Location: ****

Time: Noon

The discussion will take about 60 –90 minutes. Food and refreshments will be served. We are looking forward to meeting with you!

Please call Andrea Pritchard @ 1-403-943-7311 to confirm your attendance.

If you have any further questions, please call:

Principal Investigator: Dr. Marlene Reimer – University of Calgary, Faculty of Nursing, Associate Dean - Research (1-403-220-5839) Co-Investigator: Andrea Pritchard -MN Student, University of Calgary Nurse Clinician, Southern Alberta Hemophilia Clinic, Alberta Children's Hospital 1820 Richmond Road SW, Calgary, Alberta, Canada T2T 5C7 (1-403-943-7311) Focus Group Consent Form

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FACULTY OF NURSING

Telephone: (403) 220.7893 Fax. (403) 284-4803 Email: mareimer@ucalgary.ca

Consent for Focus Group Participation

Research Project Title:	Learning and Resource Needs and Capacities Assessment for Rural Hemophilia Health Care Providers
Principal Investigator:	Dr. Marlene Reimer University of Calgary Faculty of Nursing, Associate Dean – Research (220-5839)
Co-investigators:	Dr. Kathy Oberle University of Calgary Faculty of Nursing (220-6268)
	Andrea Pritchard University of Calgary Faculty of Nursing, MN Student (229-7311 – Hemophilia Clinic)

Sponsor: Unrestricted grant from Bayer

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information

- Purpose of this study This focus group will help to identify the learning and resource needs and capacities of rural hemophilia health care providers in Southern Alberta and South-eastern British Columbia. Identifying these needs and strengths from the view of the rural provider is important because of the unique challenges of rural health care delivery. Although hemophiliacs living in rural communities need to access both routine and urgent health care services, the learning and resources required for professionals who provide such care have not been located in the research literature.
- Description of focus group process: The focus group will invite up to 12 rural health care
 providers. The discussion will last 60 90 minutes, and will be led by a master of nursing student
 (who has experience in focus group research). Discussion will be documented by another master
 of nursing student, and audio taped for transcription.
- 3. Reason for doing research with a focus group Focus group discussions with multidisciplinary health care providers will help us to identify the unique needs and strengths of hemophilia care within the rural setting This exchange will help to identify ideas that match with workplace realities. as health care providers work together when caring for patients
- 4. Risks and benefits of being in the focus group: Participation in the focus group has minimal risk; discussions will be held with other health care providers that you may know. Benefits of

2500 University Drive N.W., Calgary, Alberta, Canada 12N 1N4 + www.ucalgary.ca/NU

participation include giving information that will guide the development of further study on this subject, including a one-day educational workshop for rural hemophilia health care providers. This information will inform others about what is required to effectively support rural hemophilia health care delivery.

- 5 Who will have access to information: Focus group discussions are confidential, and names will not be recorded. Written and audio recording of discussions will be kept in a locked cupboard at the University of Calgary, Faculty of Nursing, and will be destroyed when the study is complete. Information will be accessed only by approved study investigators, research assistant and statistical consultant.
- 6. In the event that you suffer injury as a result of participating in this research, no compensation will be provided to you by Bayer, the University of Calgary, the Calgary Health Region, study investigators, the focus group facilitator or focus group recorder. You still have all your legal rights. Nothing said here about treatment or compensation in any way alters your right to recover damages.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing you health care. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification of new information throughout your participation if you have further questions concerning matters related to this research, please contact:

Principal Investigator: Co-investigator Co-investigator: Dr. Marlene Reimer (1-403-220-5839) Dr. Kathy Oberle (1-403-220-6268) Andrea Pritchard (1-403-229-7311)

If you have any questions concerning you rights as a possible participant in this research, please contact Pat Evans, Associate Director, Internal Awards, Research Services, University of Calgary, at 220-3782.

Participant's Signature	Date	
Researcher and/or Delegate's Signature	Date	
Witness' Signature	Date	

A copy of this consent form has been given to you to keep for your records and reference.

APPENDIX C

Focus Group Questions

Focus Group Format & Questions

- 1. Introduction (5 minutes):
 - Welcome focus group members;
 - Introduction of facilitator and recorder & roles;
 - Review of research purpose, confidentiality, recording and reporting of
 - responses, and destruction of data; and
 - Overview of focus group process and conduct / group confidentiality.
- 2. Warm up & review of hemophilia (5 minutes):
 - Reflection of issues presented
 - Relate issues to research questions
- 3. Group discussion (45 60 minutes):

Open questions to guide discussion as required include:

- What do you think about when you have to take care of a hemophiliac?
- What kind of information do health care professionals need to take care of hemophiliacs?
- What do you have in place here in the hospital to help you take care of hemophiliacs?
- What resources are out there to help you take care of hemophiliacs who live in you community?

- How can the Hemophilia Treatment Centre team help you care for people with hemophilia in your community? What is working now?
- What kinds of things make it hard to connect with the Hemophilia Treatment Centre team?
- What are the challenges when you need to treat someone with fractionated blood products?
- What makes it easier to treat people with hemophilia with fractionated blood products?
- What is different about hemophilia care in your hospital compared to Calgary?
- 4. Closure & thanks (5 minutes):
 - Summary and invitation to contact research team with further comments, questions or study results; and
 - Appreciation of contribution to research project.

Hawe (2002).

Telephone Interview Cover Letter

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FACULTY OF NURSING

Telephone: (403) 220-5839 Fax: (403) 284-4803 Email: mareimer@ucalgary.ca

October 2002

Dear Colleague,

As part of a University of Calgary, Faculty of Nursing research project we are doing a series of short telephone interviews in Southern Alberta and South-eastern British Columbia on the learning and resource needs and capacities of rural hemophilia health care providers. You are recognized as a key team member in hemophilia health care delivery by study co-investigator and Hemophilia Clinic nurse clinician (Andrea Pritchard). Given your role in hemophilia health care within your community, your response is important, as information gathered in these interviews will be used to develop supports for learning and resources related to hemophilia care in your area.

What is this interview about?

Hemophiliacs living outside Calgary rely on rural health care providers for routine and emergent care. We recognize that health care delivery in this setting is unique. To provide better support between the Hemophilia Clinic and rural health care teams, we need to first appreciate and understand the learning and resource needs and strengths of rural health care providers. (A list of interview questions is found on page 2; preparation is not required)

Why is this being studied?

At present, research has not been located in the literature on the unique learning and resource needs and capacities of rural hemophilia health care providers. This study will explore and report our experience from Southem-Alberta and South-eastern British Columbia. Guided by this information, we hope to develop resources, such as a one-day workshop for rural hemophilia health care providers. What about my response?

Participation in the telephone interview should take about 15 – 20 minutes. **Telephone interview** participation is voluntary. Responses will remain confidential, be securely stored, and destroyed on study completion. All responses will be labeled a number code, and the name & number list will be known only to the research team. There is no foreseen risk to your participation in this interview. How can I participate?

 Andrea Pritchard will contact you directly at your workplace to set up an interview
 Please contact us (1-403-943-7311) if you have any questions regarding this study. You may also share your views in a rural hemophilia health care provider questionnaire that will be mailed out in the next few weeks.

2500 University Drive N.W., Calgary, Alberta, Canada T2N 1N4 • www.ucalgary.ca/NU

Responses will help guide development of learning and resource supports for hemophilia health care delivery for your area. Your time and expert views on this matter are greatly appreciated. Sincerely,

Dr. Marlene Reimer University of Calgary, Faculty of Nursing Associate Dean - Research 1-403-220-5839

Dr.Kathy Oberle University of Calgary, Faculty of Nursing Associate Professor 1-403-220-6268

Andrea Pritchard University of Calgary, Faculty of Nursing MN Student Nurse Clinician, Southern Alberta Hemophilia Clinic Alberta Children's Hospital 1820 Richmond Road SW, Calgary, Alberta, Canada T2T 5C7 1-403-943-73911 1-403-943-7393(fax) ampritch@ucalgary.ca

Questions to consider for the telephone interview (preparation is not required):

a) What learning or knowledge do health professionals need to be prepared to take care of

someone with hemophilia? How can you get this kind of education?

- b) What is in place here in your hospital/community to help you take care of hemophiliacs?
- c) What resources are out there to help you take care of hemophiliacs who live in you community? How do these resources help?
- d) How can the Hemophilia Treatment Centre team help you care for people with hemophilia in your community? What is working now?
- e) What kinds of things make it hard to connect with the Hemophilia Treatment Centre team?
- f) What are some of the challenges you face when you need to treat a hemophiliac with fractionated blood products?
- g) What makes it easier to treat a hemophiliac with fractionated blood products?

Telephone Interview Questions

1. Introduction:

With reference to the cover letter sent 2 weeks prior to telephone contact, the interviewer will review with the recruited sample the following script:

Hello (* subject's name). This is Andrea Pritchard from the University of Calgary, Faculty of Nursing, calling about the rural hemophilia study. About 2 weeks ago, I sent you a letter with a description of our study and an invitation for you to participate in a 15 – 20 minute telephone interview on learning and resource needs and capacities of rural hemophilia health care providers. Do you have any questions about the cover letter? We have previously connected from my experience as the Hemophilia Clinic nurse clinician. Because of your work in (* your community) with our hemophilia patients, your participation in this interview would be most helpful, as your responses will guide development of learning and resource development for hemophilia care in (*your community), as part of our larger southern Alberta & southeastern British Columbia service area. As stated in the cover letter, your participation in this interview is completely voluntary. I can assure you that your responses will be kept confidential, and your name will not be used in study reports. There are no foreseen risks if you take part in this interview. There is a benefit to participating in the telephone interview, as your responses will shape the questionnaire that will be sent to all key hemophilia health care providers in southern Alberta and southeastern British Columbia. including (*participant's health provider practice community). If you prefer another way to communicate your views, you can share your views in the mail-out questionnaire that will be sent to you in a few weeks time. Do you have any questions? Are you willing to take part in this short telephone interview? (If yes...) Are you available for interview now, or would you like to set up a time at a later date?

- 2. Exploration of key questions from focus group discussion:
 - a) What learning or knowledge do health professionals need to be prepared

to take care of someone with hemophilia?

b) What is in place here in your hospital/community to help you take care of

hemophiliacs?

c) What resources are out there to help you take care of hemophiliacs who

live in you community? How do these resources help?

- d) How can the Hemophilia Treatment Centre team help you care for people with hemophilia in your community? What is working now?
- e) What kinds of things make it hard to connect with the Hemophilia

Treatment Centre team?

f) What are some of the challenges you face when you need to treat a

hemophiliac with fractionated blood products?

- g) What makes it easier to treat a hemophiliac with fractionated blood products?
- 4. Clarification of focus group information:

Before we finish, I would like to make sure that I understand you thoughts on what rural hemophilia health care providers need, and what strengths are out there as well. With this in mind, I will list some ideas. With each item, let me know if you agree or disagree if this particular idea is important to you as well by answering yes or no:

(Clarify ideas, needs and capacities from focus group)

a) Guidelines on hemophilia care that cover the basics for assessment &

treatment are needed for safe and effective care.

b) Information particular to the patient, regarding status & response to

treatment and context, is required for safe and effective care.

- c) It is important to trust in the knowledge and abilities of my multidisciplinary colleagues when providing care to a person with hemophilia.
- d) It is important to trust in the knowledge and abilities of the hemophilia patients that I provide care for.

- e) Knowing one's expertise limits is important when caring for a patient with hemophilia.
- f) Awareness of multidisciplinary roles and shared expertise is important for provision of safe and effective care of hemophilia patients.
- g) The hemophilia team consists of the hemophilia clinic staff, the rural hospital staff and the patient or family with hemophilia.
- h) It is important to have a good partnership with the hemophilia clinic staff, rural hospital staff and the patient or family with hemophilia.
- i) The hemophilia clinic staff leads coordination of hemophilia patient care in rural areas.
- j) Communication of hemophilia patient care issues is a shared responsibility between the hemophilia clinic, rural hospital staff and the patient or family with hemophilia.
- k) Education Day:
- Would a multidisciplinary education day for rural hemophilia providers be helpful?
- Would you like to hear presentations from all disciplines?
- Would it be of interest for you to attend an education day in Calgary with other rural hemophilia health care providers?
- Is April 2003 a suitable month for travel to Calgary for this education day? Is Thursday or Friday a suitable day?

- 5. Closure & thank you:
 - Summary and invitation to contact research team with further comments, questions or study results; and
 - Appreciation of contribution to research project.

(Polit & Hungler, 1999, Streubert & Carpenter, 1999)

Survey Recruitment Poster

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WE NEED YOU!

INVITATION TO PARTICIPATE IN A HEMOPHILIA SURVEY FOR HEALTH CARE PROVIDERS What is it about?

As part of a University of Calgary, Faculty of Nursing research project we are conducting a survey group in your hospital to explore the unique <u>learning and</u> <u>resource needs and capacities (strengths) of rural hemophilia health care</u>

providers.

Why should I participate?

Your participation is important, as information gathered in this discussion will be used to develop supports for learning and resources in your area, such as a oneday workshop for multidisciplinary rural hemophilia health care providers.

Who can participate?

The survey is open to health care providers who are actively practicing in a community beyond a 30-minute driving commute to Calgary. This includes: *registered nurses, *physicians, *social workers, * physiotherapists, and *lab technicians & *pharmacists who manage fractionated blood products.

Those who are working in the Calgary Health Region are not eligible.

What about confidentiality?

All responses are anonymous and confidential.

How do I participate?

Please take one of the survey packages posted beside this notice. If the surveys have all been completed, please contact Andrea Pritchard at 1-403-943-7311 for additional copies.

Please return your completed survey
by ***(date)
in the attached addressed, postage paid envelope.
If you have any further questions, please call:
Principal Investigator: Dr. Marlene Reimer – University of Calgary, Faculty of
Nursing, Associate Dean - Research (1-403-220-5839)
Co-Investigator: Andrea Pritchard -MN Student, University of Calgary

Nurse Clinician, Southern Alberta Hemophilia Clinic, Alberta Children's Hospital 1820 Richmond Road SW, Calgary, Alberta, Canada T2T 5C7 (1-403-943-7311)

APPENDIX H

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Survey Cover Letter

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FACULTY OF NURSING

February 14, 2003

Dear Colleague,

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As part of a University of Calgary, Faculty of Nursing research project, we are doing a survey in Southern Alberta and South-eastern British Columbia on the learning and resource needs and capacities of rural hemophilia health care providers. Your response is important, as information gathered in this survey will be used to develop supports for learning and resources related to hemophilia care in your area. In particular, we hope to develop a one-day workshop for multidisciplinary rural hemophilia health care providers. What is this survey about?

Hemophiliacs living outside Calgary rely on rural health care providers for routine and emergent care. We recognize that health care delivery in this setting is unique. To provide better support between the Hemophilia Clinic and rural health care teams, we need to first appreciate and understand the learning and resource needs and strengths of rural health care providers.

Why is this topic being studied?

At present, no research has been found in the literature on the unique learning and resource needs and capacities of rural hemophilia health care providers. This will be explored and reported in a systematic way, to identify and share our experience from Southern-Alberta and South-eastern British Columbia. <u>Who can participate?</u>

This study includes health care providers who are actively practicing as a:

a) Registered nurse, physician, physiotherapist, social worker; OR

b) Pharmacist or lab technician with experience in managing fractionated blood products.

Health care providers who are currently practicing within the Calgary Health Region are not eligible for participation. What about confidentiality?

Participation is voluntary. Responses are anonymous, and will remain confidential. Surveys will be securely stored, and destroyed on study completion. Consent is implied with survey response.

◆Please return your survey in the enclosed addressed, postage paid envelope ◆

Your responses will help guide development of learning and resource supports for hemophilia health care delivery for your area. Please contact us if you have any questions regarding this study. <u>Your time is greatly appreciated</u>. Sincerely,

Dr. Marlene Reimer

University of Calgary, Faculty of Nursing, Associate Dean - Research (1-403-220-5839)

Andrea Pritchard

University of Calgary, Faculty of Nursing, MN Student

Nurse Clinician, Southern Alberta Hemophilia Clinic Alberta Children's Hospital

1820 Richmond Road SW, Calgary, Alberta, Canada T2T 5C7 (1-403-943-7311 or ; 1-403-943-7393- fax)

2500 University Drive N.W., Calgary, Alberta, Canada T2N 1N4

www.ucalgary.ca

APPENDIX I

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Survey

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127 Learning and Resource Needs and Capacity Assessment of Rural Hemophilia Health Care Providers

Thank you for taking time to complete this short survey. Your responses will guide the development of resources and programs for rural hemophilia health care providers.

This survey takes about 10 - 15 minutes to complete, and is for multidisciplinary health care providers who do not work within the Calgary Health Region (physicians, nurses, physiotherapists, social workerslab technologists/pharmacists who have experience with fractionated blood products are also included). Your reply will be confidential, and only reported in group form, so you will not be identified. Only the researchers will have access to the completed questionnaires.

- Before you complete this survey, please take a minute to review the attached yellow form. We are collecting this information to get a baseline idea of existing hemophilia resources.
- You will also find attached a blue response form for attendance at a complimentary Hemophilia Education Day. While your responses on this survey are greatly appreciated, you do not have to complete the questionnaire to be eligible for attendance at the education day.

Many thanks again- your responses will help to direct the development of learning resources for rural hemophilia care.

SURVEY

Learning and Resource Needs and Capacity Assessment of Rural Hemophilia Health Care Providers

A. Demographics and work information

This section will describe your workplace, professional practice and hemophilia experience.

1. Workplace location

a) Name of community:

· ****** · *****	-
	· ******

· ******	******

- □ Hospital
- □ Medical clinic
- □ Home care
- □ Other (please indicate)

2. Occupation:

- □ Registered nurse
- D Physician
- □ Social Worker
- □ Physiotherapist
- □ Lab technician (experienced in fractionated blood products)
- D Pharmacist (experienced in fractionated blood products)

3. Total years of practice experience:

- □ Less than 5 years
- □ 5-9 years
- □ 10 14 years
- □ 15 19 years
- □ More than 20 years

4. Highest level of education:

- □ Diploma
- □ Undergraduate degree
- □ Graduate degree
- Other _____

5. Hemophilia experience:

a) In your present occupation, have you ever been involved in providing health care services for hemophilia patients?

- \Box No (go to section B)
- □ *Yes routine care (regular check-up or clinic visits)
- □ *Yes urgent care (acute bleeding episodes)
- □ *Yes both routine and urgent care

IF YES \Rightarrow How many hemophilia patients have you provided routine or urgent care for?

_____# hemophilia patients provided with routine or urgent care

IF YES \Rightarrow When did you last provide health care services for a person with hemophilia:

- Within the last 12 months
- \Box Within the past 2 years
- □ Within the past 5 years
- □ Over 5 years ago

b) Please estimate the total number of hours in the last year that you have provided health care services for hemophilia patients:

Number of hours

- \Box 0 hours
- □ 1-5
- **G** 6-15
- **a** 16 30
- □ >30 hours

B. Learning and Resource Needs and Capacities

Unique challenges are faced by rural health care providers when a person with hemophilia requires health services. This section of the survey will explore what rural health providers need to support the care of hemophilia patients.

Please indicate what knowledge is required, how important that knowledge is (from your experience with hemophilia patients) and whether or not you currently have this knowledge.

1. Hemophilia Care - Learning Needs:

What knowledge do you think is required to prepare rural health care providers for hemophilia patients?

a) What knowledge <u>about hemophilia</u> is required to prepare rural health care providers to care for these patients? Check all that apply:		Rate the level of importance: 1(not at all) to 5(most important)	Is this part your curren knowledge	of nt base?
۵	basic hemophilia information	12345	Yes	No
	bleeding prevention strategies	12345	Yes	No
D	hemophilia pathophysiology	12345	Yes	No
	pain management with bleeding	12345	Yes	No
ū	clinical presentation & assessment	1	Yes	No
۵	psychosocial experiences	1	Yes	No
Q	treatment with factor concentrates	1	Yes	No
D	rehabilitation	1	Yes	No
D	typical responses to treatment	1	Yes	No
Q	atypical responses to treatment	12345	Yes	No
	risk factors of bleeding	15	Yes	No
	treatment of bleeds with medications	15	Yes	No
	secondary problems related to hemophilia	15	Yes	No

b) What knowledge <u>about the person with</u> <u>hemophilia</u> is required to prepare rural health care providers? Check all that apply:		<i>Rate the level of importance:</i> 1(not at all) to 5(most important)	Is this par your curr knowledg	rt of ent e base?
D	general health status	12345	Yes	No
D	usual response to treatment	12345	Yes	No
	individualized care plan from the Hemophilia Clinic	15	Yes	No
D	patient / family's knowledge about hemophilia	12345	Yes	No
patient /family's acquired skills & responsibilities related to hemophilia care		15	Yes	No

Comments:

2. Hemophilia Care – <u>Resource Needs:</u>

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What resources and networks do you think are required to prepare health care providers for hemophilia patients?

a) What <u>resource persons</u> are required to prepare rural health care providers? Check all that apply:		<i>Rate the level of importance:</i> 1(not at all) to 5(most important)	Are these resource pe readily ava in your workplace?	ersons ilable
۵	local health provider(s): <i>(specify occupation)</i>	12345	Yes	No
	Hemophilia Treatment Centre health provider(s): (specify occupation)	12345	Yes	No
۵	person / family with hemophilia	12345	Yes	No
	Canadian Blood Services	15	Yes	No
a	Canadian Hemophilia Society	15	Yes	No
۵	other:	15	Yes	No

b) What resource tools are required to prepare rural health care providers? Check all that apply:		<i>Rate the level of importance:</i> 1(not at all) to 5(most important)	Are these resource to readily avo in your workplace	ools vilable ?
a	assessment guidelines	12345	Yes	No
a	treatment guidelines	15	Yes	No
a	contact list of Hemophilia Treatment Centre team	1345	Yes	No
a	emergency after-hours contact list	12345	Yes	No
	basic patient teaching guidelines on hemophilia care	1	Yes	No
D	basic patient teaching guidelines on home infusion	15	Yes	No
a	triage guidelines	15	Yes	No
	general hemophilia information file	15	Yes	No
	routine hemophilia updates posted in your department	15	Yes	No
<u>a</u>	permanent health record with hemophilia patient information	15	Yes	No
	information in your department on	15	Yes	No
	each person with hemophilia	145	Yes	No
	Internet resources on hemophilia			
	Medic Alert bracelet identification	15	Yes	No

Comments:____

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2. Hemophilia Care – <u>Strengths & Capacities</u>:

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What strengths and capacities are required to assist with providing hemophilia care? Check all that apply:		<i>Rate the level of importance:</i> 1(not at all) to 5(most important)	Is this part of current practice in your workplace?
۵	Partnership with the hemophilia patient and family	15	Yes No
D	Awareness of patient specific information and care plan	12345	Yes No
	Teamwork with local multidisciplinary health care providers	15	Yes No
	Partnership with the Hemophilia Treatment Centre	15	Yes No
	Awareness of limits & boundaries associated with multidisciplinary roles	15	Yes No
D	Trust shared amongst local health care providers	15	Yes No
۵	Baseline knowledge to support hemophilia care in your hospital	15	Yes No
٥	Awareness of individual strengths that exist among local multidisciplinary health care providers.	15	Yes No
a	Awareness of supports unique to local workplace and community.	15	Yes No
	Awareness of supports beyond local workplace and community.	15	Yes No

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Comments:_____

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C. Connecting with the Hemophilia Clinic

This section will explore the connection the Hemophilia Clinic has with rural providers.

1. What members of the comprehensive care team do you need to connect with when providing rural health care services for a hemophiliac? (Check all that apply)

- □ Registered nurse
- D Physician
- □ Social Worker
- □ Physiotherapist
- □ Lab technician
- Other (please indicate) ______
- □ No contact required

2. Identify the barriers and facilitators in connecting with the Hemophilia Clinic comprehensive care team:

What is needed to for you to connect effectively with the Hemophilia Clinic comprehensive care team? Check all that apply:		Rate the level of importance: 1(not at all) to 5(most important)	Is this part current pro in your workplace	t of actice ?
۵	Awareness of Hemophilia Treatment Center program and services	12345	Yes	No
	Readily available Hemophilia Treatment Centre contact information	15	Yes	No
۵	Established peer-to-peer communication link	12345	Yes	No
D	Communication by telephone & pager	12345	Yes	No
	Voice mail	12345	Yes	No
a	Hemophilia Treatment Centre receptionist ("live person") to direct calls	15	Yes	No
۵	24-hour communication link with Hemophilia Hematologist	1	Yes	No
	Communication by fax	12345	Yes	No
۵	Communication by e-mail	15	Yes	No
a	Communication by postal mail	1	Yes	No
	• Other:	1	Yes	No

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Comments:____

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D. Hemophilia Care – Treatment with Fractionated Blood Products:

1. Do you have experience in your clinical practice with fractionated blood products? **Ves No** (if no, go to question #2)

If yes, check the kind of product(s):

- □ Factor VIII
- □ Factor IX
- □ Other
- 2. Identify the facilitators and barriers to treating hemophiliacs with fractionated blood products in your rural area:

What do you need when a person with hemophilia needs treatment with fractionated blood products? Check all that apply:		<i>Rate the level of importance:</i> 1(not at all) to 5(most important)	Is this experienced in your current practice?
۵	step by step guidelines for ordering fractionated product	15	Yes No
۵	step by step guidelines for administering fractionated product	12345	Yes No
٦	indications for treatment	15	Yes No
٦	rationale for treatment	1	Yes No
a	hemophilia basic knowledge	1	Yes No
D	hemophilia pathophysiology	1	Yes No
a	individualized care plan from the Hemophilia Treatment Centre	1	Yes No
a	information on fractionated product availability	15	Yes No
	communication link with the Hemophilia Treatment Centre	15	Yes No
a	after-hours communication link with the Hemophilia Treatment Centre	15	Yes No
a	communication link with the Canadian Blood Services	15	Yes No
a	local institutional guidelines that match Hemophilia Treatment Centre	15	Yes No
	support from local multidisciplinary colleague:	15	Yes No
a	(specify) other:	15	Yes No
E. Possibilities for Supports -

This final section will look at possible solutions to meet the learning and resource needs of rural hemophilia health care providers.

- 1. Would you find it helpful to attend a complimentary one-day, multidisciplinary workshop at the Hemophilia Clinic in Calgary to learn more about hemophilia care?
 - □ Yes (*If YES, please complete the attached <u>blue RSVP form</u> for this workshop, and go on to question #2)
 - \square **No** (*If NO*, please go on to question #2)

2. Please check all resources that may be helpful:

- one-day, multidisciplinary workshop in Calgary
- □ 1 2 hour, inservice provided by the Hemophilia Clinic at your hospital
- □ 2 4 hour, on-site inservice provided by the Hemophilia Clinic at your hospital
- \square 1 2 hour telehealth videoconference
- □ 2 4 hour telehealth videoconference
- □ other:___

(specify)

From the list of resources that may be helpful, rank the 3 most important items:

- ____ one-day, multidisciplinary workshop in Calgary
- ____ 1 2 hour, inservice provided by the Hemophilia Clinic at your hospital
- 2 4 hour, on-site inservice provided by the Hemophilia Clinic at your hospital
- 1 2 hour telehealth videoconference
- 2 4 hour telehealth videoconference
- _____ other:

(specify)

Who would be most helpful to hear presentations from in the education session?

- D Hemophilia Nurse
- Hemophilia Hematologist
- □ Social worker
- Rural health care provider:______(specify)
- □ A representative of Canadian Blood Services
- □ Physiotherapist
- Derson / Family with hemophilia
- □ A representative of the Canadian Hemophilia Society
- D Pharmacist
- □ Lab tech from blood bank

From the list of education session presenters, rank the 3 most important:

- ____ Hemophilia Nurse
- ____ Hemophilia Hematologist
- ____ Rural health care provider:______(specify)
- ____ Social worker
- ____ A representative of Canadian Blood Services
- ___ Physiotherapist
- ____ Person / Family with hemophilia
- ____ A representative of the Canadian Hemophilia Society
- ___ Pharmacist
- ____ Lab tech from blood bank
- ____ Other:_____

Thank you for your time. Your responses will help guide development of educational programs and resources for rural hemophilia health care providers.

Please return this questionnaire (along with the yellow response sheets) in the self-addressed, postage paid envelope by March 15th, 2003.

If you have further questions about this study, please contact Andrea Pritchard @ 1-403-943-7311 or ampritch@ucalgary.ca

APPENDIX I

Survey Follow-up Letter

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EACULTY OF NURSING

Telephone: (403) 220-5839 Fax: (403) 284-4803 Email: mareimer@ucalgary.ca

March 1st, 2003

UNIVERSITY OF

RE: Learning and Resource Needs and Capacities of Rural Hemophilia Health Care Providers Investigators: Andrea Pritchard, Dr. Marlene Reimer & Dr. Kathy Oberle, Faculty of Nursing

Dear Colleague,

Thank you for reviewing the questionnaire sent to you on February 14th for rural

hemophilia healthcare providers. Please return your completed survey in the

previously enclosed self-addressed envelope by March 15th. Your response will

guide the development of hemophilia resources and programs for caregiver

partners. Your time and response to this questionnaire is greatly appreciated.

Many thanks again.

- 5-

Sincerely, Andrea Pritchard, RN, BN (MN Student- Faculty of Nursing) Nurse Clinician, Hemophilia Clinic 1-403-943-7311 1-403-943-7393 (fax) ampritch@ucalgary.ca

2500 University Drive N.W., Calgary, Alberta, Canada T2N 1N4 • www.ucalgary.ca/NU

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Education Day Invitation

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Hemophilia Education Day

We are planning a complimentary hemophilia education day for multidisciplinary health care providers. This will be held in Calgary at the Alberta Children's Hospital.

For those who are interested yet unable to attend in person, we will also be providing a telehealth video link.

If you would like to attend this education session in person or by telehealth, please indicate your preferences below:

Please check all that apply-

DATE	LOCATION		
Thursday April 24 th	 Calgary Telehealth at your local hospital 		
Friday May 2 nd	 Calgary Telehealth at your local hospital 		

NAME:	
Occupation:	
Workplace	
Address:	
Phone:	Fax:

E-mail: _____

⇒If traveling from out of town, will you need accommodation?

🗆 Yes 🗆 No

There is limited funding to provide attendees with accommodation at a hotel nearby the Alberta Children's Hospital.

Please return this response form to Andrea Pritchard by fax

1-403-943-7393

You will be contacted directly by e-mail or fax regarding the confirmed education session date and accommodation arrangements.

Please direct any questions to Andrea Pritchard at1-403-943-7311

(Nurse Clinician- Southern Alberta Hemophilia Clinic)

This Hemophilia Education Day has been generously funded through an unrestricted grant from Bayer.

Final Education Day Program

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Multidisciplinary Hemophilia Education Day Invitation

The Southern Alberta Hemophilia Comprehensive Care Team would like to invite you to a complimentary hemophilia education day for multidisciplinary health care providers from Southern Alberta and Southeastern British Columbia. <u>This will be held in Calgary at the Alberta Children's Hospital</u> on Friday May 2nd from 0800-1500h.

For those who are interested yet unable to attend in person, we will also be providing limited telehealth session . Details regarding this distance learning opportunity

will be available through your local telehealth coordinator:

Region I- Louise Wilson 382-6227 (Medicine Hat); Region II- Cheryl Birch 529-8852 (Lethbridge); Region III- Sybil Young 943-7587 (Calgary); Region III- Michele McCarthy 933-8524(Black Diamond); Region IV-Deb Bexfield 309-5729(Red Deer)

Please complete and fax this form only if you are planning to attend the education day in Calgary at the Alberta Children's Hospital.

NAME: ______ Occupation: ______ Workplace Address: ______ Phone: ______ Fax: _____

E-mail:

📾 If traveling from out of town:

a) Will you need accommodation?
□ Yes □ No

b) Are you willing to share a room with a colleague?
Solution Yes No No *Please specify who you are willing to share with:

There is limited availability to provide complimentary accommodation for out-oftown attendees at the Fairmont Palliser Hotel.

Your response is required as indicated below to confirm your request.

Please return this response by April 21st to Andrea Pritchard

by FAX @ <u>1-403-943-7393</u>

You will be contacted directly by e-mail or fax regarding confirmation of your registration and accommodation.

If you have further questions, contact the Hemophilia Clinic at 1-403-943-7311

or e-mail Andrea.Pritchard@calgaryhealthregion.ca

Hemophilia Education Day- Proposed Agenda for Friday May 2nd, Alberta Children's Hospital Solarium – 4th Floor

All sessions are open to all disciplines

0800-0830: Arrivals & coffee

0830 - 0900: Welcome to all & opening with "<u>Hemophilia Care: The</u> Family Perspective" (Hemophilia Clinic & Canadian Hemophilia Society)

□ 0900 - 0945: "Hemophilia Basics and Emergency Care" Local & telehealth presentation by Hemophilia Hematologist (Dr. M.-C. Poon, Southern Alberta Hemophilia Clinic Medical Director) 0945-1000: Question period for local and telehealth audience

□ 1000 - 1045: "Factor Replacement Therapy "

Local & <u>telehealth</u> presentation by Hemophilia Nurse & Lab Technologist (Andrea Pritchard & Angie Fitzsimons - Southern Alberta Hemophilia Clinic)

1045-1100: Question period for local and telehealth audience 1115 - 1130: *Coffee break & end of telehealth sessions*

1130 – 1215: a) "<u>Hemophilia Care: Putting it all Together</u>"- overview of hemophilia resources & open networking session regarding hemophilia care related issues (facilitated by Nurses Morna Brown, Andrea Pritchard & Pat Klein); or

b) "Hemophilia Care in the Lab"- overview of fractionated products & open networking session regarding hemophilia care related issues (facilitated by Hemophilia Lab Technologist Angie Fitzsimons & Canadian Blood Services- Pat Luttmer)

1215 - 1300: Networking lunch

After lunch, lab technologists will learn more about fractionated products in their breakout session while touring the CBS facilities from 1300 – 1430h.

Otherwise, all afternoon sessions are open to all disciplines

1300h-1345h: "Hemophilia Care of Muscles & Joints"

Hands-on session for assessing bleeds and assisting with rehabilitation (facilitated by Hemophilia Physiotherapist – Jenny Aikenhead)

1345-1430h: "<u>Hemophilia Care of the Person & Family</u>" Overview of psychosocial issues in acute and chronic care of hemophilia (*facilitated by Hemophilia Social Worker- Ruanna Jones*) 1430-1445: Coffee and evaluations

1445-1500h: Closing remarks & wrap up

This Hemophilia Education Day has been generously funded through an unrestricted grant from Bayer.

APPENDIX L

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Education Day Pre and Post-test

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Learning and Resource Needs and Capacity Assessment of Rural Hemophilia Health Care Providers: *Baseline Questions*

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Please complete these questions before participating in the focus group, telephone interview or mail-out survey. Your responses to these 5 questions will help us to guide the development of education programs for rural hemophilia health care providers.

Your participation in this questionnaire is voluntary, and does not affect your participation in this study. Responses will remain anonymous.

We will ask the same questions again after the Hemophilia Partners Education Session (to be scheduled in 2003 in Calgary) to evaluate this upcoming learning program.

Please rate the following:

1. As a health care professional, I know what to do to provide safe and effective care for someone with hemophilia.

2. As a member of a multidisciplinary health care team, my co-workers know what to do to provide care for someone with hemophilia.

122	35
(strongly disagree)	(strongly agree)

3. I know how to connect with the health care team from the Hemophilia Clinic Treatment Centre when their support is needed.

4. I know how to access resources (such as educational materials) that I need to provide care for someone with hemophilia.

1-----5 (strongly disagree) (strongly agree)

5. I know how to deal with fractionated (blood) products that are needed to provide care for someone with hemophilia.

1-----5 (strongly disagree) (strongly agree)

⇒ * Have you completed this survey before? (circle one) yes / no *

Thank you for your time. Your responses will help guide the development of educational programs for rural hemophilia health care providers. Please return this questionnaire directly to the research assistant, or in the addressed, postage paid envelope.

If you have further questions, contact Andrea Pritchard at 1-403-943-7311.

APPENDIX M

Education Day Evaluation

Over 50 health care professionals from southern Alberta and southeastern British Columbia were in attendance on site (*n*=34) (see Table 14) or by telehealth videoconference (5 rural hospitals). Presentations were given by the Canadian Hemophilia Society, Canadian Blood Services, Transfusion Medicine and hemophilia specialists representing medicine, nursing, physiotherapy and social work. Presentations included topics such as hemophilia emergency care, factor replacement therapy, care of muscles and joints, and care of the person and family. Larger multidisciplinary presentations were combined with smaller discipline specific working groups. While the presence of all collaborative care partners at hemophilia education programs was recognized as important, families were not specifically targeted in this initial formal attempt at rural educational outreach for hemophilia care. However, this is a consideration for future related initiatives.

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Occupation	Frequency	%	
Registered Nurse	15	44	
Lab Technologist	. 10	. 29	
Physician	5	15	
Physiotherapist	2	6	
Other	2	6	
	occupational		
	therapist, medical		
	receptionist		
TOTAL	34	100%	

Table 14: On Site Education Day Attendees

While the comprehensive care team voiced commitment to supporting the learning and resource needs of rural hemophilia providers, compounding workrelated responsibilities constrained the specialty clinic team from providing onsite in-services at all 11 rural communities. A generous unrestricted industry grant assisted to overcome this barrier and supported key rural hemophilia providers to attend a complimentary education day at the tertiary care hospital where the Hemophilia Clinic is located. This method of delivery was further supported in principle by study participants, as findings indicated that connecting with other rural hemophilia providers in a shared education session would be beneficial for their own learning and networking purposes. Rural providers' identified readiness to learn by telehealth in-service as their second overall choice was noted and incorporated in the program. Such readiness may be further supported by reports of effective rural multidisciplinary continuing education as provided by telehealth (Richardson-Nassif, Swartz, & Reardon, 2002). Distance continuing education has been reported as successful in promoting both competence and multidisciplinary collaboration amongst participants (Aoun & Johnson, 2002; Cornish et al., 2003).

Pre-test survey (see Appendix L) was offered to all participants (*n*=72) prior to involvement in each stage of the research process. As all respondents indicated they had not previously completed this evaluation form, it is concluded that there were no multiple respondents for the pre-test. Combined participants from all 3 research stages (N=76) yielded a 95% pre-test response rate. Post-test survey

had a response of 77% (n=26), drawn exclusively from those who participated in the Calgary Multidisciplinary Education Day (N=34). Post-test results indicate 9% (n=3) respondents had also completed the pre-test survey. Pre and post-test survey consisted of 5 key items describing readiness for rural hemophilia care (see Table 15). Such items were rated on a 5-point Likert scale with scores ranging from 1 (strongly disagree) to 5 (strongly agree).

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Table 15:	Hemophilia Multidisciplinary Education Day- Pre and Pos	t Test
	Survey	

Readiness for	Pre	Post	Overall
Rural Hemophilia Care	n=72	n=26	Improved
(and related themes)			Readines
			S
1. As a health care professional, I	M=3.014	M=3.962	
know what to do to provide safe	SD=1.014	SD=.445	个 76.1%
and effective care for someone	60.3%	79.2%	
with hemophilia.			
(objective & subjective			
knowledge)			
2. As a member of a	M=2.972	M=3.3846	
multidisciplinary health care	SD=.903	SD=.804	
team, my co-workers know what			
to do to provide care for			
someone with hemophilia.			
(team roles)			
3. I know how to connect with the	M=3.111	M=4.5	
health care team from the	SD=1.41	SD=.86	个69.1%
Hemophilia Clinic Treatment			
Centre when their support is			
needed.			
(communication & team roles)			
4. I know how to access	M=2.764	M=4.3077	
resources (such as educational	SD=1.193	SD=.884	个64.2%
materials) that I need to provide			
care for someone with			
hemophilia.			
(communication & partnerships)		14 0 0077	
5. I know how to deal with	M=2.972	M=3.8077	A 70 40/
fractionated (blood) products that	SD=1.138	SD=1.096	个 /8.1%
are needed to provide care for			
someone with hemophilia.			
(objective knowledge)			A 74 00/
Summary of overall ratings	M=2.967	M= 3.992	个 74.3%

Open-ended comments from Multidisciplinary Education Day participants evaluated this educational session to be informative, comprehensive, and wellorganized. Attendees indicated that take-home educational resources provided by the Canadian Hemophilia Society were relevant and deemed to be effective as a potential workplace resource. These resources included handouts from education sessions, Canadian Hemophilia Society produced "All About Hemophilia" (2002), "All About von Willebrand Disease" (2001), "Factor First" (2003) posters, and "Hemophilia Emergency Care" booklets (Region VI Hemophilia Nurses, 2001).

"I felt this went exceptionally well. It was very informative for all areas of health care. The best way to handle situations is to educate and you have definitely done that today. Thanks. Exceptional jobs done by all."

I value the time and effort in bringing such a great learning opportunity together. Each presenter provided a valuable piece of the complete picture. Thanks to all. I found it helpful to learn through shared experiences. Would suggest additional scenarios and addressing 'the five' (who what when where & why) continue to allow us the 'how' that makes the difference to us · as professionals and to the families we care and share with.

Evaluations indicated a high level of satisfaction with the education session. Furthermore, participants indicated an increase in knowledge to facilitate provision of rural hemophilia care. Pre and post-test evaluations of this intervention indicated an increase in hemophilia care facilitators: safe care,

teamwork, communication, resource accessibility and hemophilia treatment. Such facilitators reflected all 5 main themes (objective knowledge, subjective knowledge, communication, team roles, and partnerships). Given such positive response and overall impact noted in the 74.3 % improvement in hemophilia care readiness, it is thereby recommended that this resource method be considered in future planning of education sessions for multidisciplinary rural hemophilia providers. A similar approach has been demonstrated in an Australian study by Chang and colleagues (2002), whereby collaborative, continuing mental health education established by academia and rural providers has been found to be both effective and cost efficient. In hemophilia care, such program development should also include consideration of learning and resource needs and capacities as identified by the rural health care providers themselves. Attendees indicated a preference to attend routine learning sessions on an annual basis to ensure continued competence in hemophilia care.

Education Day Considerations

The Multidisciplinary Education Day was made possible through an unrestricted grant from a pharmaceutical company that produces factor concentrates. The sponsor was formally thanked at the session, and participants were aware that the accommodations and education day related expenses were covered by this grant. No explicit advertising was displayed at this event. Provision of such support made this day possible, as multidisciplinary health care providers in attendance identified that they may not have been able to attend if

additional costs were incurred beyond their missed day of work and other travel related expenses.

"Should be done on a regular basis so all hospital personnel can better deal with these patients. Well done. Please thank (the sponsor) for all that they provided."

Furthermore, while the content of the education day was planned to incorporate preferences indicated by survey respondents, the time allocated for a speaker with hemophilia was limited on that day by that speaker's own multiple commitments: workplace demands prevented this speaker from spending more time at the session. Consideration must be given to such multiple commitments experienced by persons living with hemophilia. Compounding roles as patients, family members, and contributors to the workplace and community must be recognized and accommodated when placing an additional request on the invaluable time of those who are living with hemophilia.

Finally, the creation of such programs must also account for the compounding demands shared by hemophilia providers in the rural and urban settings. Rural providers identified that their attendance was restricted by the availability of coverage by colleagues: the rural staff replacement pool was reported to be limited, and in many cases providers could not attend an out-of-town session due to such restrictions. Urban hemophilia providers identified demands of similar nature, as this intervention development and implementation took place amidst ongoing service requirements for acute and chronic hemophilia care needs. The

impact of such sessions must be considered within the broader context of hemophilia care delivery to ensure that such programs are indeed worthwhile.

APPENDIX N:

UNIVERSITY OF CALGARY ETHICS BOARD APPROVAL LETTERS

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FACULTY OF MEDICINE

Office of Medical Bioethics Heritage Medical Research Building/Rm 93 Telephone: (403) 220-7990 Fax: (403) 283-8524

2003-03-03

Dr. M.A. Reimer Faculty of Nursing University of Calgary PF 2272 Calgary, Alberta

Dear Dr. Reimer:

RE: Learning and Resource Needs and Capacities Assessment of Rural Hemophilia Health Care Providers - Ms. Andrea Pritchard (MN Student)

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Grant-ID: 16538

Your request to modify the above-named protocol has been reviewed and approved.

I am pleased to advise you that it is permissible for you to extend the completion date to March 2003, based on the information contained in your correspondence received by us on January 28, 2003.

A progress report concerning this study is required annually, from the date of the original approval (2002-07-02). The report should contain information concerning:

- (i) the number of subjects recruited;
- (ii) a description of any protocol modification;
- (iii) any unusual and/or severe complications, adverse events or unanticipated problems involving risks to subjects or others, withdrawal of subjects from the research, or complaints about the research;
- (iv) a summary of any recent literature, finding, or other relevant information, especially information about risks associated with the research;
- (v) a copy of the current informed consent form;
- (vi) the expected date of termination of this project.

Thank you for the attention which I know you will bring to these matters.

Yours sincerely, -

Christopher J. Doig, MD, MSc, FRCPC Chair, Conjoint Health Research Ethics Board

CJD/mc

c.c. Adult Research Committee Ms. Andrea Pritchard

www.ucalgary.ca



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FACULTY OF MEDICINE

Office of Medical Bioethics Heritage Medical Research Building/Rm 93 Telephone: (403) 220-7990 Fax: (403) 283-8524

2002-07-02

Dr. M.A. Reimer Faculty of Nursing University of Calgary PF 2272 Calgary, Alberta

Dear Dr. Reimer:

RE: <u>Learning and Resource Needs and Capacities Assessment of Rural Hemophilia Health Care Providers</u> <u>Student: Ms. Andrea Pritchard</u>

Grant-ID: 16538

The above-noted research proposal, the consent form, the telephone interview guideline and the questionnaire cover letter have been submitted for Committee review and found to be ethically acceptable. Please note that this approval is subject to the following conditions:

- (1) a copy of the informed consent form must have been given to each research subject, if required for this study;
- (2) a Progress Report must be submitted by 2003-07-02, containing the following information:
 - (i) the number of subjects recruited;
 - (ii) a description of any protocol modification;
 - any unusual and/or severe complications, adverse events or unanticipated problems involving risks to subjects or others, withdrawal of subjects from the research, or complaints about the research;
 - (iv) a summary of any recent literature, finding, or other relevant information, especially information about risks associated with the research;
 - (v) a copy of the current informed consent form;
 - (vi) the expected date of termination of this project;
- (3) a Final Report must be submitted at the termination of the project.

Please note that you have been named as the principal collaborator on this study because students are not permitted to serve as principal investigators. Please accept the Board's best wishes for success in your research.

Yours sincerely

Christopher J. Doig, MD, MSc, FRCPC Chair, Conjoint Health Research Ethics Board

cc: Adult Research Committee Ms. Andrea Pritchard

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3330 Hospital Drive N.W., Calgary, Alberta, Canada T2N 4N1

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