ROSACEA: A REVIEW OF FAMILY HISTORY
A COMMUNITY OF ORIGIN

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ROSACEA: A REVIEW OF FAMILY HISTORY AND COMMUNITY OF ORIGIN

by

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ABSTRACT

This descriptive study was conducted utilizing a cohort of diagnosed rosacea patients from a group dermatologists' clinic serving a population in Eastern Newfoundland. The etiology of rosacea is unknown, therefore, this study was conducted to answer two primary questions: (1) is there a family history of rosacea and (2) can rosacea be traced to a particular ancestral community of origin for the population under study? A literature review reveals that little has been documented regarding family history and ethnicity. Additional data was concurrently collected including basic demographics, frequency and severity of triggers, exposure to sun, quality of life and the occurrence of other skin conditions.

One hundred and fifty-two patients with rosacea were drawn from new or returning patients to the dermatology practice during the spring, summer and fall of 2000. As each patient checked in with the receptionist s/he was asked to participate in this research by completing a self-administered 106 question survey.

Results revealed a strong family history of rosacea in 67% of the cases. There emerged a community or region of origin in a particular area of the catchment area. The origins of the majority of the settlers to Conception Bay North and Trinity Bay South are from the southwest area of England. The population is of fair skin with dark and light brown hair and blue eyes. The average age of diagnosis is in the fifth decade of life. Occupational work of the respondent group was conducted primarily indoors, sun screen use was absent or insignificant in childhood and adolescence. The occurrence of other

skin conditions was present in one quarter of the cases. The frequency and severity of triggers are comparable to previously reported data.

The results point to a strong familial relationship, leading to the conclusion that genetic etiology is probable. This information together with knowledge of ancestral community of origin provides an area to begin genetic research.

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CHAPTER I - INTRODUCTION

Rosacea is classified as a chronic, inflammatory skin disease that primarily affects the centre of the face in a symmetrical fashion.[1-4] An appearance of permanent sunburn is a characteristic of rosacea, hence the name is derived from the Latin meaning rosy.[1, 5] The condition affects blood vessels and sebaceous follicles and is characterized by erythema, telangiectasia and eruptions of papules and pustules and in a minority of cases, glandular sebaceous hyperplasia.[1,5,6]

Rosacea occurs in 1.3 million Canadians and 13 million Americans, which is about 4% of the population. [7-10] It is of unknown etiology.[11] Clinical experience reveals that rosacea occurs primarily in fair skinned people and is believed to be found in those of Celtic descent.[1,2,7-10] Epidemiological studies on the issue of ethnicity are limited.

Those who specialize in treating rosacea consider it to be a fascinating disease. They are treating a medical condition of unknown etiology so therefore are engaged in an area of medicine where there still remains a wide range of proposed causes. Physicians derive a high degree of satisfaction in providing resolution to the chronic episodic symptoms and experience a great deal of gratitude from patients whose treatment meets with success.

There are many misconceptions surrounding rosacea, one is that this disease is a form of acne. While it may have the appearance of red bumps or papules on the face, it is not acne but is a disease itself. Hence, the term acne rosacea is not an accurate one.[10,11]

Another misconception is that rosacea is a result of over-consumption of alcohol.[3,12-14] This can be the cause of social discomfort for those who have this disease.

While, it is true that alcohol is one of a number of foods and drinks that can trigger an inflammatory response, rosacea is not associated with the over-consumption of this substance. A single drink or ingestion of a small portion of an "edible trigger" can prompt a flare up in many, leading to the "red-looking complexion". [2,3,10,13-15]

There are negative side effects to this disease beyond the physiological manifestations of it. The aforementioned is evidence of individuals being unable to fully participate in all gustatory aspects of social engagement, hence rosacea has an impact upon lifestyle and socialization.[10,12,16]

The timing of the appearance of rosacea is not always identifiable. Those with this condition may have had no previous experience with other skin conditions or even with teenage acne.[12] It may take many visits to a physician before it is established that *the* condition under investigation is, in fact, rosacea. The literature suggests two things: that there is a skin type which is predisposed to developing this disease, and that there is a period of pre-rosacea.[5] However, not all vascular lability or the tendency to blush easily - an overt sign of pre-rosacea, may lead to progressive changes in the skin that are characteristic of rosacea. Why some and not others? Hereditary factors are a possibility but have not been previously examined and references to family history are mainly based upon clinical experience and anecdotal evidence.

As stated, rosacea begins as a tendency to blush easily and after a long period of time it progresses to inflammation or redness that varies in degrees of intensity and permanence, eruptions of papules, pustules and skin thickening as the disease progresses.[13]

Permanent disfigurement may result.[17] Consequently, the urgent need of individuals to be accurately diagnosed and treated is understandable.

CHAPTER II – A GENERAL STATEMENT OF STUDY OBJECTIVES

Most of the literature on the topic of rosacea concerns diagnosis, management, treatment and causal agents. There has been little comprehensive epidemiological data available on this dermatological disease, especially in the area of family history and ancestral community of origin.[18] The majority of evidence cited in journals on family history and ethnicity has been gathered from clinical experience. A review of medical periodicals reveals that only a limited number of epidemiological studies or surveys have been conducted such as The Rosacea Awareness Program (RAP) in Canada (1999)[16]and the National Rosacea Survey in the United States (1996).[15,19] Also, Berg and Liden, produced comprehensive epidemiological data on several aspects of rosacea in 1989.[20] However, the variable of "family history" was not included in these surveys. In 1998, Katz compiled a summary of the most recent literature and his report lists only one reference to family history.[18]

This disease is of unknown etiology. [2,5,11,13,16] Hence, the question: Is there evidence of genetic predisposition to rosacea? In order to examine this issue, the first step is a review of family history. A positive outcome would provide a foundation for further research in this area.

This research project was designed to address two major objectives. The researcher sought to determine the incidence of family history of rosacea among a population with diagnosed rosacea and to explore family name and community of origin of the population under study.

A number of minor objectives were also examined while gathering data on the primary areas of study and they are as follows:

- general demographics;
- exposure to sun;
- occupational setting;
- frequency and severity of a range of reported triggers;
- quality of life regarding feelings and attitudes surrounding relationships and socialising;
- occurrence of other skin condition in the subject and his/her family.

CHAPTER III – LITERATURE REVIEW

3.1 Introduction

Rosacea is a chronic disease of unknown etiology.[2,4,5,11,13,16] The usual case of rosacea presents in adulthood.[2,14] It generally appears as episodic flare ups followed by remissions that progress in stages throughout the course of the disease, although it is not always multiphasic in every case.[21] Both males and females are affected.[1,2,12,19,20] However, it occurs less frequently but more severely in males, at an approximate ratio of 3:1 females to males.[11,14,22]

It manifests itself dermatologically, often in response to a trigger, such as a particular food, an extreme in hot or cold temperature, or stress.[12,14,16] The onset is gradual, primarily around the central portion of the face, and secondarily around the neck, chest and eyelids. Because it is an episodic condition for which there is no cure, the treatment is aimed at control of the many symptoms of which the most prevalent is an erythema or redness on the face. Szlachcic et al report that it appears also on the neck and legs.[23]

Rosacea is generally seen in adults in the fourth and fifth decade of life.[11,14,24] However, there is evidence of its appearance in younger adults and even in children. The younger patients present with the earlier milder stages, while the more severe symptoms are generally seen in older age groups. In the last five years there have been reports of children with rosacea aged two, nine and eleven years.[18,25,26]

It's stated that the condition occurs more commonly amongst those from Northern European ancestry [2,10,13,14,18] but there is no objective study to support this.

3.2 Symptoms

The spectrum of the disease may range from a mild, temporary form to a more severe condition.[14] Progressive manifestations occur from the mild state of erythematous or redness to papules, pustules and later, in some, to hyperplasia.[2,21,27] Manifestations are classified by Stages 1 to 4.[11,12,14,15] Consequently the symptoms that are apparent at any one time in this disease are associated with the stage of the disease that the individual is in. It is interesting to note that few patients complete the full course of the disease with most progressing to Stage 2 or 3.

The onset of rosacea is gradual, so consequently the symptoms are not readily apparent or identifiable in the earliest stages. In its mildest form, rosacea is manifested by the tendency to flush, hence the reference to rosy.[1,2,8,10] It may progress to a point where it causes a permanent redness known as erythema, found usually on the central area of the face, although it may involve the neck, forehead, and eyelids. This occurs because the facial capillaries have an increased response to a number of factors or "triggers" such as heat, cold, alcohol, spicy food, plus an array of other stimuli which result in a flushing or pre-rosacea.[14] Patients in this pre-rosacea stage may complain of skin that is sensitive to cosmetics and certain sunscreens and report a stinging or burning as a result of chemical or physical stimuli.[11]

Stage One

Stage One rosacea, as described above, involves periodic redness or transient flushing (erythema) which may flare up in response to a common trigger such as sunlight, spicy food, alcohol, cold weather or stress, resulting in increases in skin temperature.

Stinging or burning may be reported by some patients. The redness of rosacea or erythema may become permanent after many years, although at times the redness may fade leaving a background of fine tiny blood vessels referred to as telangiectasia.[9,13,14]

Stage Two

Stage Two or erythematous/telangiectatic type rosacea involves the development of telangiectasia and more persistent erythema. This is also referred to as the vascular stage.[10,13,14]

Stage Three

Stage Three or papular type rosacea includes the development of papules, pustules, cysts and nodules. Often concomitant ocular involvement is seen in this stage.[2,13,14] Lesions are generally limited to the face along with persistent, firm, pale pink lymphedema on the cheeks or periocular region and seldom occur elsewhere on the body.[17,28,29] Rosacea does not affect the back or chest, although it has been reported that disseminated lesions may occur on the chest, wrists and legs.[17] Some develop edema in the nasolabial folds.[10]

Stage Four

Only a small minority progress to stage four or glandular/ hyperplastic type rosacea.[12] Rhinophyma is the final stage of rosacea and is seen more commonly in middle-aged men than women.[2,5,8,13,14,18] Phyma is a Greek work pertaining to a mass, bulb or swelling.[11] W.C. Fields and Jimmy Durante's bulbous noses were the result of rhinophyma, or the edematous outcome of advanced rosacea.[5,10] This stage is characterized by moderate to severe flushing, numerous telangiectasias and rhinophyma, a hyperplasia of the

soft tissues and sebaceous glands of the nose, producing a purplish red lobulated thickening of the lower portion of the nose with dilated pores.

Once present, rhinophyma can become a permanent alteration of the epidermis of the face and does not resolve without surgery.[2,4,10] Incidentally, some men occasionally develop rhinophyma without having experienced a previous history of rosacea.[5]

While rosacea occurs primarily on the centre of the face, there are other areas of the face where it manifests itself as outlined in Table 1 from the (American) National Rosacea Society Survey.[15, 22]

Table 1: Manifestation of Rosacea by Area of the Face.

Area	*Males (%)*	*Females (%)*
Chin	*20*	*49*
Nose	*85*	*77*
Cheeks	*68*	*87*
Forehead	*41*	*42*
Rhinophyma	*21*	*8*

Source: National Rosacea Society Survey, 1996 [15,22]

3.3 Diagnosis

There is no diagnostic test for rosacea.[13,18] Diagnosis is based upon clinical findings and a differential diagnosis is required to exclude any number of other possibilities. Early symptoms of rosacea may be mistaken for normal flushing or sunburn and hence, rosacea is often mis- or undiagnosed. A 1999 survey of 2,340 Canadian rosacea patients conducted by the Rosacea Awareness Program (RAP) [15] revealed that diagnosis is not easily made by the family doctor. For example, 53% of the cases required a specialist to make the diagnosis. Only 15% of the patients were diagnosed by the family doctor and 24% were self diagnosed and confirmed by a family doctor.[15]

Rosacea is a clinical diagnosis due to the absence of a specific laboratory test to confirm its presence. Differential diagnosis should include acne, atopic and perioral dermatitis, systemic lupus erythematosus, seborrheic dermatitis, carcinoid syndrome and erythematosis, sarcoidosis, drug induced photosensitivity, and pityrosporum folliculitis. [10, 12-15, 24, 30-32]

Rosacea is distinguished from acne by a number of factors: the age of the patient and absence of comedones, the occurrence of acne along the mouth, chin and jawline, as opposed to rosacea which is found on the cheeks, periorbital and perioral.[1,27]

In summary the following assists the clinician in diagnosing rosacea: cutaneous appearance and distribution, characteristic course, target population, and response to pharmacology. Early diagnosis is important due to the fact that resulting fibroplasia from long term untreated rosacea may result in disfiguring hyperplasia.[9]

3.4 Other Skin Conditions

Most of the time rosacea presents without a preceeding history of other skin conditions, although during the course of the disease the patient may require treatment for another concurrent skin condition.[12,13] The following co-existing conditions have been commonly reported: acne, seborrheic dermatitis and eczema, although it is reported that it is uncommon to see acne concurrently with a flare up of rosacea.[12,14,20]

3.5 Sun Damage

The examination of the role of sun damage in the development of rosacea is scanty and therefore there is no solid evidence regarding its relationship to this disease. Anecdotal evidence indicates that fair skinned individuals who may have experienced moderate to

severe sunburns in their lifetime may have an increased risk for developing or aggravating rosacea.[31] Upon examining the literature one will find contradictory reports concerning the effect of the sun on those who have rosacea.[7] Most North American patients surveyed report that sunlight is a trigger that has the potential to cause a flare up. As a result, individuals with rosacea take care to cover up, avoid sunbathing, use sunscreen and generally limit their exposure to the sun. In contrast to this, a Swedish study reported that sun did not exacerbate the disease but rather helped it.[20] Until more complete data is collected on the role of the sun in the development, impact and control of this disease, anecdotal evidence and the limited available scientific information provides an unclear and contradictory picture.

3.6 Ocular Involvement

Not only are the symptoms of rosacea apparent on the epidermis of the face but ocular manifestations can affect from 3 to 58% of the patients at some time in the course of this disease in the form of keratitis, conjuctivitis, blepharitis, and episcleritis.[1,5,8,11,13,14,33,34] Eye involvement may be mild or severe and is often overlooked, due to unrecognized, undiagnosed or misdiagnosed rosacea hence the range in the reports of incidence.[11,14]

Ocular manifestations are not generally seen in the early stage but occur as the disease evolves into the late chronic phase.[35] The patient may present with common vague subjective complaints such as burning, scratchiness, or feelings of something in the eye. Objective observations include mild lesions such as blepharitis and conjuctival, redness, soreness and grittiness of the lid margins, hyperemia, iritis, episcleritis, and superficial

punctate keratopathy [5,14,33] Severe lesions include corneal neovascularization, scarring and thinning and even corneal perforation.[2] Kligman estimates that men with rhinophyma almost always show signs and symptoms of ocular rosacea and that 75% of women who are over forty-five years of age have ocular rosacea concurrently with facial manifestations, especially in the peri-menopausal period.[35] Terezhalmy and Chen reports that ocular rosacea is as common as 50% in patients. [24,27] Most common symptoms are erythema and telangiectasia of the eyelids [36] followed by moderate blepharitis and conjunctivitis.[36]

Ocular involvement is often overlooked because the focus of treatment for rosacea is usually centered on facial complaints. A family physician may or may not make the link between a patient requesting treatment for an eye complaint with a concurrent problem of rosacea, especially since ocular rosacea can occur alone or prior to skin lesions of rosacea.[5]

3.7 Treatment

The treatment goal is to control rather than cure the disease.[10,14,16,36,38] There are two major areas of treatment used in medical practice for rosacea: (i) avoidance of triggers and masking manifestations and (ii) drug therapy.[16,36,39]

3.7.1 Avoidance of Triggers

Avoidance of triggers and masking the redness, which follows exposure to a trigger, is the primary form of treatment available in Stage One rosacea.[14,38] The most frequently reported triggers are various food items, extremes of temperature and stress.[14] However, avoidance of triggers is not easily attainable because of the common pervading

nature of these items. While one can maintain control over and avoid foods, such as red wine and spicy foods, it is more difficult to control external triggers such as cold weather and stress. As a result, avoidance of triggers is not sufficient to control rosacea.

3.7.2 Drug Therapy

Drug therapy is used to treat Stage One, Two and Three rosacea.[16] The treatments of this multi-phasic disease are usually successful in arresting its progress in the second and/or third stage, but do not cure it.[2,36] The therapy consists of a combination of oral and topical antibiotics which have been utilized to bring about a remission.[14,16,24,36,38,40]

Figure 1. Evolution and Treatment of Rosacea

<table>
<tr><th colspan="5">EVOLUTION OF ROSACEA AND TREATMENT</th></tr>
<tr><th>Flushing</th><th>Facial Erythema</th><th>Telangiectasia</th><th>Papules or Pustules</th><th>Rhinophyma</th></tr>
<tr><td colspan="5">Avoid triggers and irritants</td></tr>
<tr><td colspan="5">Drug therapy to reduce flushing</td></tr>
<tr><td rowspan="5"></td><td colspan="4">Psychological counselling and/or drug therapy</td></tr>
<tr><td colspan="4">Camouflage makeup</td></tr>
<tr><td colspan="4">Topical metronidazole</td></tr>
<tr><td colspan="2" rowspan="2"></td><td>Oral antibiotics (intermittent or continuous) tetracycline and others</td><td></td></tr>
<tr><td>Isotretinoin (severe cases)</td><td></td></tr>
<tr><td colspan="2">Laser</td><td></td><td>Laser</td></tr>
</table>

Source: Shear NH, Journal of Cutaneous Medicine & Surgery, 1998;Vol 2 Suppl 4: S4-1.

Initially the physician will begin with six to twelve weeks of oral antibiotics selecting from any of the following: tetracycline, minocycline or erythromycin. This treatment is followed by the use of topical antibiotics in the form of a metronidazole

cream or gel, one of the more successful and commonly used topical preparations successful against the inflammatory, papulopustular and erythema component of rosacea.[1,7,16,25,38,39,41,42] Apart from the anti-inflammatory characteristic of the antibiotics, the mechanism of action of the antibiotic is unknown, but its success in the control of rosacea in the absence of other effective measures is endorsement for its continued use. With the topical gel and cream, the sought after results are achieved without long-term systemic drug use. Its use led to a successful decrease in the dosage of systemic antibiotics. This treatment regimen was equally effective in treating children with rosacea with improvement in one to three months.[25,43] On occasion, patients will require intermittent repeat use of oral antibiotics when the topical creams cease to control symptoms.[36]

Topical tretinoin and isotretinoin (Accutane) is used in cases that do not respond to the aforementioned drug therapy.[14,16,36,41] The mechanism for action is unknown, but the results are such that its use brings the acute flare up under control.[14,42] Recent clinical research indicates that high doses of topical tretinion (0.25%) in an ethanolic solution minimizes the manifestation of papular/ pustular rosacea within a relatively short time.[27] This treatment was also effective in cases of rosacea secondary to overuse of steroid creams applied to the face.[26]

Steroids will not resolve the erythema or telangiectasia, pustules or papules which are characteristic of rosacea and if used over the long term may exacerbate or promote the manifestations of rosacea.[11] Steroids are not a drug of choice in the treatment of this

disease.[11,26,27,42] An extensive description of pharmacological treatment and dosing for rosacea has been outlined by Singer.[40]

3.7.3 New pharmacological treatments

A new quinolone antimicrobial agent, fleroxacin, used to treat severe acne in Japan, was successful in the treatment of solid edema of rosacea. The pharmacological properties of fleroxacin reported in mice were anti-inflammatory in nature and displayed a suppression of reticuloendothelial function. A case report by Uhara et al demonstrates resolution of edema in the periorbital area in a 53 year old male who had not responded to minocycline as treatment for erythema, telangiectasia and solid facial edema.[44] Because the improvement of facial edema of this patient after use of fleroxacin was immediate, where it had previously been resistant to minocycline, fleroxacin appeared to be beneficial. This example may be the beginning of investigation into the use of quinolone antimicrobial agents as an alternative in the treatment of solid edema of rosacea.[44]

3.7.4 Laser therapy

Laser therapy is another tool used in the management of rosacea.[45] While this is not a treatment to control rosacea, it is effectively utilized to repair the facial changes due to chronic inflammation of the face.[15,36] Pulsed dye vascular laser therapy is useful for telangiectasia in most patients and in a few patients the persistent flushing may improve as well. [36] While rosacea can progress to become a permanent alteration of the epidermis of the face, the recent use of laser therapy decreases the incidence of permanent damage.[45]

3.7.5 Psychological/Social Implications

The manifestations of rosacea are found to have an effect on the psychological wellbeing of those with this disease.[3,30] Facial redness often accompanied by papules and pustules may result in discomfort when socializing, working or interacting with others. Participation in strenuous sports or outdoor activities, eating or drinking specific foods are all lifestyle related situations that may require limitations due to rosacea. Hence, rosacea has an impact upon lifestyle. There is the misbelief that rosacea symptoms are caused by overindulgence in alcohol or poor personal hygiene, but the condition is not due to either of these practices. However, knowledge that co-workers, strangers or others may imagine that this is the case, has a negative impact upon the rosacea patient. Consequently, these elements individually or in combination cause psychological discomfort.[10,14,15] The National Rosacea Society has documented the following adverse feelings experienced by those with this disease: 70% are embarrased, 56% feel robbed of pleasure or happiness, 75% feel low self-esteem, 57% believe it affects their social life, and 69% report frustration.[15]

3.8 Etiology

The etiology of rosacea is unknown.[8,13] Suggested causes include seborrhea, hormonal and psychological factors, gastrointestinal tract infections, riboflavin deficiency, an immunologic reaction to *Demodex folliculorum*, a vascular disease and climactic factors.[14] A review of the literature reveals a progression of thought on the cause of rosacea. To date, nothing is conclusive and a number of schools of thought are circulating in the medical community regarding the etiology of this condition.

Contact with specific items trigger a response that leads to flushing and subsequent progressive symptoms of rosacea. A number of known triggers include, sunlight, alcohol, extreme temperatures, hot or spicy foods and emotional stress. [14,15,20]

Histopathologic findings associated with rosacea include vascular dilation, edema, perivascular infiltration of histiocytes, lymhocytes and plasma cells, and granulomas.[9,46] Although the histological findings of rosacea are documented, the issue regarding the cause or causes of rosacea remains unexplained. Exploration of causes covers a wide variety of queries ranging from *Demodex folliculorum* mites to *Helicobacter pylori* (H. Pylori) bacteria.

Demodex Folliculorum Mites

The infestation of mites has been referenced in the literature back as early as 1961 in an article by Ayres & Ayres.[47] The interest and level of investigation of this agent and its role as a potential contributing factor to rosacea has increased in the last decade. Litt reports "the presence of the mite *Demodex folliculorum*, a normal inhabitant of human skin, has also been examined, but study results have been inconclusive."[9,48] Wedi and Kapp, [49] and Pena and Andrade Filho [50] continue to examine the possibility of the *Demodex folliculorum* mite acting as a pathogenic agent in rosacea.

Although a *Demodex folliculorum* mite population has been noted as being present in large numbers in those with rosacea.[7,9,16,50,51] The difficulty remains identifying and describing the action of the parasite on the host and the pathogenic mechanisms which alter the host tissues by the alleged pathogen, ie. *Demodex folliculorum*. [28,48] As a point of interest is appears that the majority of medical papers reporting on *Demodex folliculorum*

mites are from journals outside of North America such as Italy, Egypt Turkey, Finland, Brazil and a smaller number from the United States. These have appeared from 1997 to 2000. In spite of this level of research, to date the role of *Demodex folliculorum* mites is felt by some investigators to be of importance while others feel causal association cannot be assigned.[13,14]

Helicobacter Pylori

Another agent has been under investigation regarding its role as a causative agent of rosacea. Helicobacter pylori (H. pylori) infection of the gastric mucosa has been commonly found in individuals with rosacea and therefore it has been investigated to determine its role in the etiology of this disease. It is believed that rosacea could be one of the major extragastric manifestations of H. pylori infection in the stomach.

Litt reports that it has been suggested that H. pylori stimulates the synthesises of gastrin which may stimulate flushing.[9,52] Many studies have been conducted to determine the plausibility of this theory. However, study results are contradictory and therefore its role remains inconclusive.[13,53] As in the research regarding rosacea and Demodex mites, the investigation of H. pylori has been ongoing, and it appears research has been conducted in areas primarily outside of North America and Great Britain. The research is varied in its outcome. Rebora [54] and Utas et al [55] propose a relationship between H. pylori and symptoms of rosacea, and report that once H. pylori was eradicated the symptoms of rosacea disappeared in a large majority of patients. Others report research results that provide there is no evidence of a strong causal relationship.[3,39,56-62] In a recent letter Rebora and Drago clarified their position by stating that they are not making the case that

H. pylori is the *cause* but rather it is their belief that it may play a role in the production of papules and pustules.[63]

Another study by Jones et al reported no relationship to H. pylori.[58] Comparison of rosacea patients to a control group revealed that the incidence of H. pylori did not differ.[9] Hence, it is felt that the eradication of H. pylori and improvement of rosacea is not causative.[58] Son agrees that a casual relationship between H. pylori and rosacea does not exist.[57] His group found no statistically significant difference in the prevalence of H. pylori infection in rosacea patients (65%) compared with that of Korean adults (75%). They recommend that larger studies be conducted.[57]

Szlachcic et al argue that the H pylori virulence factors, (CagA) and cytokines (TNF alpha, IL-8) are possibly the major pathogenic factor in rosacea patients.[23] Eradication of H. pylori removes the cutaneous and gastrointestinal symptoms. Hence, they believe that CagA positive H. pylori and various H. pylori related cytokines contribute to the pathogenesis of rosacea.[23]

Sharma et al studied subjects with rosacea and a matched control group both of which were tested for H. pylori and found no significant difference in the sero prevalence of infection between the two groups.[56] The reports that patients with rosacea have an increased prevalence of H. pylori infection causing rosacea are inconclusive.[3] However the controlled studies of Bamford, Son, Sharma and Jones appear to indicate that this bacterium is not the link to rosacea.[39,56-58,64] If it were so, certainly the majority of those with H. pylori would exhibit the manifestations of rosacea as well.

Wedi and Kapp compiled a table outlining all of the studies on this topic by country from 1994 to 1999. Some are double blind and, overall, it is felt that the evidence is not strong enough to indicate a causative relationship.[49] The researchers in these studies used metronidazole, omeprazole and clarithromycin, of which two of these metronidazole and clarithromycin, would have a positive effect on treating rosacea in the absence of H. pylori. It may well be that resolution or improvement of rosacea symptoms are a result of the anti-inflammatory action of the antibiotics that are prescribed to treat H. pylori and not due to the eradication of it and possibly, improvement of rosacea is secondary to the treatment of H. pylori.

3.9 Prevalence

Examination of the distribution of rosacea in the general population may reveal clues to researchers pointing them to a specific area for further investigation of a cause. The following provides an overview of the incidence of rosacea in the general population, how it is distributed by age and gender and any familial occurrence.

3.9.1 General Population

The figures given in textbooks and journals regarding the incidence of rosacea are inconsistent. Textbooks report a prevalence to be 3%-5% which translates into 1.3 million cases in Canada, 13 million in the United States, or one case of rosacea for every twenty individuals in the general population.[7-10] However, others consider this to be grossly underestimated.[9] Based upon clinical evidence of (1) frequent episodes of flushing with persistent erythema, (2) papulopustules and (3) telangiectasia, Litt feels that rosacea occurs in at least 30% of the population.[9] It is reasonable to consider that the prevalence is not

reliably reported due to the number of cases that may not be recorded due to number of undiagnosed mis-diagnosed disease[33] as reported by the National Rosacea Survey and the Rosacea Awareness Society [15] and the Rosacea Awareness Program (RAP) [16].

A Swedish epidemiological study was conducted by Berg and Liden who examined 809 randomly selected individuals.[20] From this group, eighty-one cases of rosaea were diagnosed. This represents a prevalence of 10%. A Polish paper reported rosacea to occur in approximately 2% of the population. [23] Wedi and Kapp reported that rosacea affects 12% of the geriatric population. [49] It is not surprising to see an increased prevalence in the elderly considering that the likelihood of correct diagnosis is stronger as one ages and symptoms progress.

Between 1953 and 1966 it was noted that rosacea comprised 1 to 2% of all new skin cases seen at St. John's Hospital for Diseases of the Skin. [18]In 1944 and 1946 rosacea comprised 0.75% of the cases at the Department of Dermatology, University of Copenhagen, Denmark. [18] One can conclude that the incidence is wide ranging from 5 to 30 percent.

3.9.2 Age

Rosacea is a disease of adulthood with the average age of patient groups in the mid forties. [9, 11-13,16,31] Age of onset is reported to be in the fourth to fifth decade.[9, 11-13,16,31] data from the National Rosacea Society gathered in a survey of 2,279 respondents found age of onset to be in the forties. Although it is rare in children, it has been reported in those as young as two years of age. [13,20,25,43]

3.9.3 Gender

Rosacea is distributed disproportionately by gender.[1,5,22] In the epidemiological study by Berg et al, the gender distribution of the diagnosed population was 77.5% female and 22.5% male, reflecting a distribution of 14% female and 55 male in the general population.[20] An examination by Hogan et al of all patients presenting to general dermatology clinics in a Saskatchewan teaching hospital between 1983 and 1985 revealed 117 rosacea patients with a 3:1 female to male ration.[14,18]

The uneven distribution of male/female ratio reported in the lieterature has been considered by some to be due to the fact that females may more readily seek medical intervention for a facial skin problem than males, and subsequently there are more females diagnosed. However, the Berg and Liden study supports the female/male ratio and discounts these claims.[20] The individuals in this group were not seeking medical treatment but were volunteers participating in a large, randomly selected sample of the population. In this sample the ratio of rosacea was still 3:1 female to male.[20]

3.9.4 Familial Occurrence

In the medical journals, there are scanty reference and little research on family history of rosacea. Dermatologists agree that the predisposition to flush easily and the tendency of rosacea to occur among family members indicates that rosacea may be inherited [8,9]. The only report summarizing epidemiological data is that compiled by Katz at the Division of Dermatology, Sunnybrook Health Sciences in 1998. [18] Katz assembled

reports that are in published medical journals and provides information that only one researcher mentioned the variable of family history. Rebora notes references in a study of rosacea and H. pylori [54] and in a separate journal article, Gratton reports a 30% family history.[5] Zuber states that approximately 40% of sufferers have a family member with the disorder.[15] The likely familial predisposition has not been noted other than through observation.

Actual research that has been conducted is two surveys. One by the Canadian Rosacea Awareness Program in 1998 in which 7,000 questionnaires were distributed (30% response rate), while the other was the National Rosacea Survey conducted in the United States which reported from data collected from 2, 279 individuals with rosacea. Family history reported in this study is 40%. [22]

In a study of 106 prepubertal children with steroidal induced rosacea, 20% had a first degree relative with rosacea. Half were determined by history taking and the other half by examination of family members.[26]

In summary, the literature reports are limited in the information they offer on family history and rosacea.

3.9.5 Ethnicity

There are no epidemiological studies regarding the incidence of ethnicity and rosacea. However, the literature reports that those of Celtic or Northern European descent appear to be most at risk, while those of Latino and Asian descent are at less risk, and African-Americans are seen rarely with rosacea.[5,8,12] The general statement regarding ethnic occurrence in the population points to Northern Europeans and those of Celtic

descent. However, a literature review on the topic of rosacea reveals research which has been conducted in many countries including Turkey, Brazil, Korea and Egypt as well as in Germany, Great Britain, Sweden, Finland, France, Poland, Italy and the United States. Son, Katz and other sources report that rosacea is mainly found in those of northern European ancestry and in fair-skinned individuals, but research is conducted in countries with a variety of ethnic groups, such as, Africans, Asians and Koreans. [13,18,57] This indicates that the disease occurs in many nationalities, but has been repeatedly reported that it is a condition occuring primarily in Northern European groups. Without objective data, Celts, particularly English and Scottish, remain the group most referenced in textbooks.

Litt reports that those of the following national ancestry have elevated rates of rosacea: Irish, English, Scandinavian, Scottish, Welsh, Polish, Lithuanian, and Balkan ethnic heritages. He gives no reference or source in the table that lists these under national ancestry.[9] This conclusion is derived from clinical experience and again, as yet there has not been an objective examination of this area.[18]

There is a certainty however, that rosacea is not commonly seen in black skin. Only a small number of references to this ethnic group are available.[3,11,12,13] In 1935, Hanxen examined the medical charts of 11,729 African-American patients.[18] Only 0.08% or nine patients had a diagnosis of rosacea. It appears that it is not as common as among fair skinned individuals. The role of melanin is thought to play a role in masking cutaneous erythema making it uncertain why it is not seen in this ethnic population. This raises two questions: is this because it was misdiagnosed or because there were no cases among this ethnic group? Browning raises the query that if rosacea is underdiagnosed in the white

population, perhaps it is missed in the African-American population due to the skin pigmentation.[33]

In conclusion, one cannot say definitively that this is a disease of just one group. Based upon the literature, the researchers make these statements in the absence of clear documentation. Son states that the epidemiology in Korea is unclear, has not yet been established and awaits further investigation. [57] This appears to be the case for all other ethnic groups as well.

CHAPTER IV - METHODS: COLLECTION AND ANALYSIS OF DATA

4.1 Design

A descriptive, population-based study was conducted to collect and examine historical and current data on multiple variables related to rosacea. The primary area to be examined was that of (i) family history and (ii) name and community of origin of each patient's parents and grandparents. In addition, data was collected on variables related to this disease in six areas, including demographic information, history of sun exposure, frequency and severity of triggers, quality of life and incidence of other skin conditions.

The study collected data on variables that have been reported in the medical literature such as gender, physical features, including eye colour, hair colour, skin type, menopausal status, age and age of diagnosis, frequency and severity of triggers, and stage of rosacea. A number of other variables were examined in this study, that have not been extensively reviewed in the literature including sun exposure, family history, occurrence of other skin conditions of the patient and patient's family members, community of origin and quality of life. This study did not collect data on ocular rosacea, involvement of *Demodex folliculorum* mites, H. pylori and pharmaceutical treatment or therapies.

Ethical considerations

The study received approval from the Human Investigation Committee of Memorial University of Newfoundland.

4.2 The Instrument

The instrument utilized in this study was a 106 question self-administered questionnaire (Appendix A)

The instrument collected data on variables divided into six sections: demographics; community of origin/ethnic background; history of sun exposure; severity and frequency of triggers; lifestyle; and family history.

Table 2. Data Collected

Quantitative Data	Qualitative Data
Age:	Physical demographic characteristics
Current age	Family community of origin and name
Age of onset	Skin Type
Age of diagnosis	Type and severity of triggers
Number of hours in sun	Quality of life
Number of sun burns	
Number of family members with diagnosed or signs and symptoms of rosacea	
Self and relatives with other skin conditions	
Stage of rosacea	

Data was collected for four generations, including fourteen relationships: first degree relatives such as mother, father, siblings, offspring, and other extended family members such as maternal and paternal grandparents, aunts and uncles and first cousins.

A pilot was conducted to test the questionnaire in which respondents 1 - 25 participated. Three of these did not return the questionnaire. The pilot revealed that collection of data for great-aunts and uncles was not productive due to the high number of "unknown" or "no answer" responses, which provided little useful data. Questions related to these relatives were omitted from the remainder of the study. Additionally, two questions, which had been overlooked, were added to the questionnaire: (i) children of subjects with rosacea and occurrence of other skin conditions. The pilot group was contacted by telephone to ask questions that had been omitted and to test-retest the questions on sun exposure.

A number of questions used were adapted or taken directly from standardized questionnaires, these are listed in Table 3.

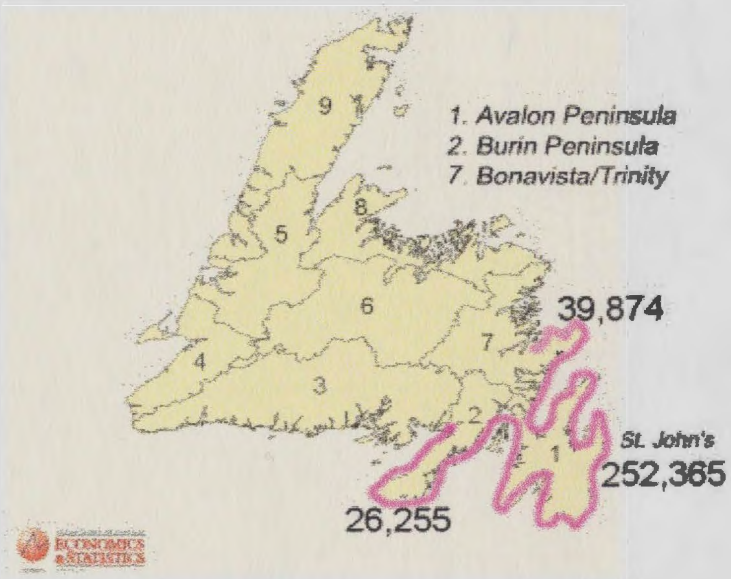
Table 3. Questions used in questionnaire extracted from standardized questionnaires

Questions in Questionnaires	Borrowed from Standardized Questionnaires
Qualitative	
How embarrassed or self conscious have you been over the last week? Q 60	The Dermatology Life Quality Index (DQLI) *Source:* Novartis
Did rosacea prevent you from shopping, socializing, having sexual relations, or interactions with friends, co-workers, partners, siblings and parents.? Q 61 - 69	Practical use of a disability index in the routine management of acne, *Source:* Motely RJ, Finlay AY. Clinical Experimental Dermatology 1992; 17: 1 – 3.
	The Quality of Life Measurement in Dermatology: a practical guide (QOL) Source: Finlay, Br J Derm. 1997 136 (3): 305 – 14
Quantitative	
Skin Type Chart Q 40	Pediatric Dermatology *Source:* Schiachner LA, Hansen RC vol 2 chapter 32, Physical Injury by Lane, Alfred, p 1620.
Type of Sun Burn Q 41 -43 Time in the sun during leisure hours Q 37- 39	The Sun Exposure Survey, Special Survey Divisions, Statistics Canada
Use of sun screen and type of artificial tanning methods Q 32, 33,34	The Sun Exposure Survey, Special Survey Divisions, Statistics Canada

4.3 Subjects

The group studied is a sample of a rosacea patient population. The sample is comprised of individuals who have been diagnosed with rosacea and are patients of a group dermatology clinic in St. John's, Newfoundland. The population of the catchment area is 318,494 or ~ 60% of the population of 538,823 for the province. This includes the Bonavista, Burin and Avalon Peninsulas (Figure 2).

Figure 2. Catchment Area



Source of Population data: Population estimates July 1, 1996-2000. Statistics Canada Demography Division, September, 2000 via NF Statistics Agency.

The sample 110 subjects consisted of a consecutive series of rosacea patients attending laser clinics participated in the study. Of these there were twenty-four males and eighty-six females between the ages of 30 and 76 years with stage 2, persistent erythema and Stage 3, telangiectasia/ papulopustular level rosacea.

Patients of the practice who were recruited for this study are normally referred from primary care physicians throughout the eastern part of the province of Newfoundland (Figure 2). The diagnosis of rosacea was made by one of three experienced dermatologists.

4.4 Data Collection

Collection of data occurred over a nine-month period. The responses were collected using a self-administered 106 question questionnaire.

The subjects were patients returning for follow-up appointments to the dermatology clinic. Upon arrival and check in they were asked by the researcher or research assistant if they would like to take part in a study on the topic of rosacea. This required a one- time involvement on the part of the patient for a total of fifteen to twenty minutes to complete the questionnaire. Patients were provided with information about the research project. After reviewing it, if they wished to participate, they gave their written consent and completed the questionnaire in the clinic or opted to take it home for later return.

Assistance was available if and when required. The instrument was easy to use for the respondent in that it required a short time to complete, there was sufficient room in which to enter data, and questions were easy to understand. There were no problems with the instrument or conditions under which it was administered. There were no foreseeable risks, discomforts or inconveniences anticipated or experienced by the participants who

completed the questionnaire. No treatments were involved in the study, and normal treatment continued. A total of one hundred and fifty-four patients were approached. Two declined to participate and forty-two did not return the questionnaire.

4.5 Data Entry and Analysis

Responses were numeric or narrative. The following numerical assignments were given to variables: unknown (99), no response (66) and not applicable (33). Textual data was entered as text as it was provided in the questionnaire. Considerable time and effort was spent to reduce errors in computer entries. Each questionnaire was assigned a unique identifier number. Responses were keyed directly from the questionnaire Numerical data was coded for purposes of aggregating data. Each variable was edited by analysing the total responses using a bar graph and a statistical frequency print out in order to locate omissions or unusual data entries. Rechecks of omissions or odd numerical entries were made against the applicable questionnaire. Random checks were made to recheck the accuracy of data entering. Only data received was reported, non responses were excluded. The responses were analysed using SPSS 9.0, Statistical Program for Social Sciences [66], to determine frequencies and other descriptive statistics.

CHAPTER V – RESULTS

Between April and December of 2000, 154 patients were approached and given background information about the study. Of these, 152 (98%) agreed to participate. However, forty-two questionnaires were not returned. The demographic profile for age and gender of non-returns was similar to that of the participants. The community of origin for non-participants was not available.

Table 4. Age and Gender of Non-respondents

	N	%	Age (Average)
Males	10	27.0	43.4
Females	27	73.0	46.9
Unknown	5		
Total	42		45.9

The data from the 110 questionnaires was entered in the computer and analysed. The following provides the results of the analysis in two parts: Part A, general demographic data, family history, community of origin distribution and frequency of family names information and Part B, other minor study objectives including sun exposure, frequency of triggers, quality of life, and other skin conditions.

Part A

5.1 General Demographic Data

The analysis of the demographic data profiles a population which closely matches other populations and samples reported in the literature and general textbooks. The

group was a predominantly female, middle-aged, pre-menopausal, Canadian population, of which the majority displayed recessive eye colour, blue and hazel/green, and light or dark brown hair (Table 4). The female to male ratio of 3:1.

Signs and symptoms are seen in the early adult stages and up to the eighth and ninth decade of life which is evidenced in this group, with the average age of diagnosis being in the early forties (42 years).

The group under study has had the disease for an average of 10 years, consequently, their responses to questions regarding triggers and experiences with rosacea are drawn from having long-term experience with the disease. All respondents, except two, manifested symptoms of stage 2 and stage 3 rosacea. The remaining two had stage 4 or rhinophyma. No early stage or pre-rosacea were included in this group. Table 5 displays this information according to gender and total group.

Table 5 . Demographic characteristics of the population

Variable	Total	Females	Males
Gender	N = 110	N = 86 78.2%	N = 24 21.8%
Average Age (yrs)	46.86 range:30 - 76	46.08 range: 31 - 76	49.6 range: 30 - 76
Age of Diagnosis (yrs)	41.96 range: 20- 72	41.81 range: 20 - 72	42.50 range: 26 - 72
Hair Colour	%	%	%
Black	4.5	2.3	12.5
Dark Brown	28.1	40.7	33.3
Light Brown	30.1	45.3	29.2
Blonde	4.6	5.8	8.3
Auburn	2.0	2.3	4.2
Red	2.6	3.5	4.2
No answer	1.8	0.0	8.3
	100	100	100
Eye Colour	%	%	%
Brown	16.4	17.4	12.5
Grey	4.5	3.5	8.3
Green/Hazel	35.5	38.4	25.0
Blue	41.8	40.7	45.8
No answer	1.8	0.0	8.4
	100%	100%	100%
Number of years with rosacea	10.1 range: 2 - 45	9.3 range: 1 - 40	13.3 range: 2 - 45
Menopausal Status		%	
Pre		73.7	n/a
Menopausal		13.3	
Post		9.6	
Place of Birth			
Canadian/Newfoundland	100%		
Stage of Rosacea	%		
Stage 2	50		
Stage 3	48		
Stage 4	2		

5.2 Family History

The major objective of this descriptive study is to determine if there is a family history of rosacea in a population of diagnosed rosacea patients. The family members in this examination include fourteen relative groupings, spanning four generations, which includes parents and siblings, offspring, maternal and paternal aunts and uncles, grandparents and first cousins. The respondents were asked to identify if each of these relatives had (i) diagnosed rosacea or (ii) signs and symptoms of rosacea. The results have not separated these because determination of the accuracy of each response would require a dermatologist's diagnosis. This would not be practical to undertake during data collection but diagnosis of family members may be incorporated in a later research study into family history.

The data revealed that there is a strong family history, 67 % or 74 of the 110 respondents reported that they have one or more family members with diagnosed rosacea or with signs and symptoms of rosacea. Of the 67% who report that they have at least one family member with signs and symptoms of rosacea, 74.3% have multiple family members with rosacea ranging from 2 to 16 relatives per family. Table 6 illustrates this breakdown.

Table 6. Number of respondents with family members exhibiting either diagnosed or signs of rosacea

Number of family members with rosacea per respondent	N	Percent (%)
None	36	32.7
Family Members with Rosacea	74	67.3
One	19	17.3
Two to four	32	29.1
Five to nine	21	19.1
fourteen	1	0.9
sixteen	1	0.9
Total	110	100.0

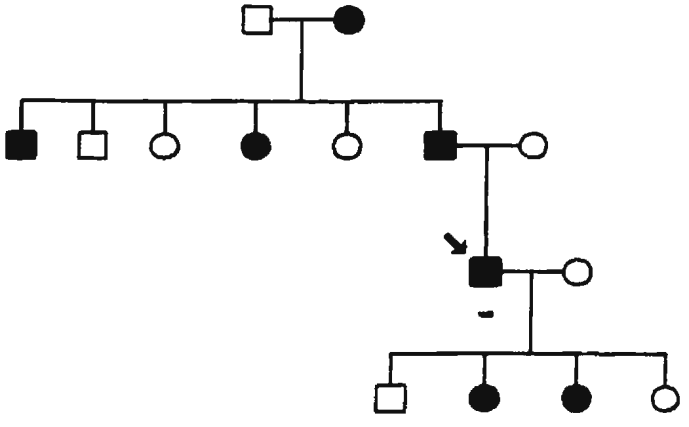
The specific familial relationship as reported by the 110 respondents is shown in Table 7. It is interesting to note that although the gender ratio is 3:1 female to male, more respondents report that his/her father (41.9%) has/had signs and symptoms of rosacea than his/her mother (24.3%).

Table 7. Number of respondents with specific relatives manifesting signs of rosacea

Relationship to respondents	Number	Percent (%) with Family History n = 74	Percent (%) of total n = 110
Father	31	41.9	28.2
Mother	18	24.3	16.4
Brothers range 1 - 4	23	31.9	20.9
n =15 : 1 brother			
n = 7: 2 brothers			
n = 1: 4 brothers			
Sisters range 1 -3	24	32.4	21.8
n = 12: 1 sister			
n = 7 : 2 sisters			
n = 5 : 3 sisters			
Both brothers and sisters			
n = 4: 1 B and 1 S	13	17.6	11.8
n = 2: 2 B and 1 S			
n = 2: 1 B and 3 S			
n = 2: 2 B and 2 S			
n = 2: 2 B and 3 S			
n = 1: 1 B and 2 S			
Offspring range 1 - 7	16	21.6	14.5
Female:10 Males: 5			
n = 9: 1F n = 4: 1 M			
n = 1: 2F n = 1: 2 F			
Both: n = 1: 4 F and 3 M	1	1.4	.1
Maternal Aunts	12	16.2	10.9
Maternal Uncles	10		9.1
- Both Maternal Aunts & Uncles	4	13.5	
Paternal Aunts	14	18.9	12.7
Paternal Uncles	15	20.2	13.6
Both Paternal Aunts and Uncles	10	13.5	9.1
Maternal Grandmother	5		4.5
Maternal Grandfather	5	6.7	4.5
Paternal Grandmother	2	6.7	1.8
Paternal Grandfather	1	2.7	.1
Maternal First Cousins 6 F; 6 M	12	1.4	10.9
Paternal First Cousins 6 F; 8 M	14	16.2	12.7
		18.9	

Figure 3 illustrates the data from one respondent, indicated by the arrow, who reports diagnosed or signs and symptoms of rosacea in four generations beginning with a paternal grandmother and including, one paternal aunt, one paternal uncle, his father, the respondent and two of his daughters. His grandmother reportedly has/had rosacea. She had six children and three have signs and symptoms of rosacea. One of these six is the respondent's father who has signs of rosacea. The respondent has diagnosed rosacea and he has four children, of whom two daughters have signs and symptoms of rosacea. Of the seven family members in this pedigree who were identified as having signs and symptoms of rosacea, there are three first degree relatives of the respondent who have signs and symptoms of rosacea, ie, offspring, siblings and/or parents. A first degree relative is one who has close genetic relationship.

Figure 3. A pedigree illustrating the occurrence of rosacea in one respondent's family.

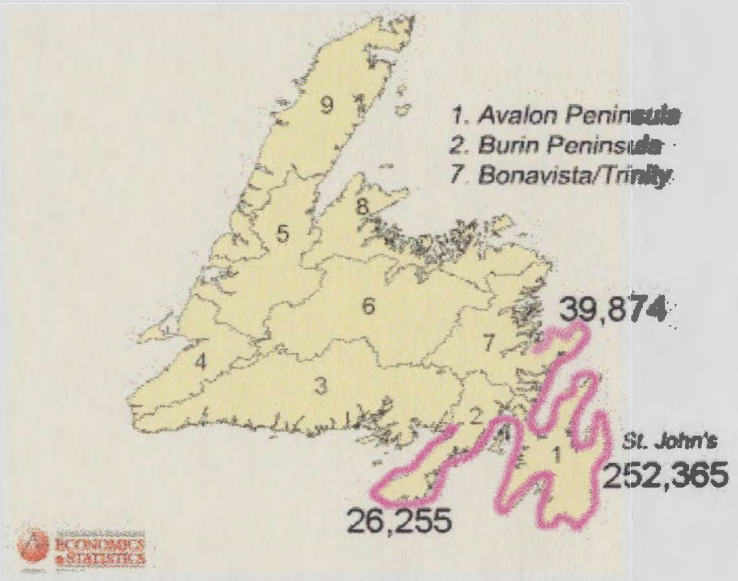


5.3 Community of Origin

In addition to looking at family history of this group, the researcher also examined the data to determine where the respondents and their ancestors, i.e. paternal and maternal grandparents, came from.

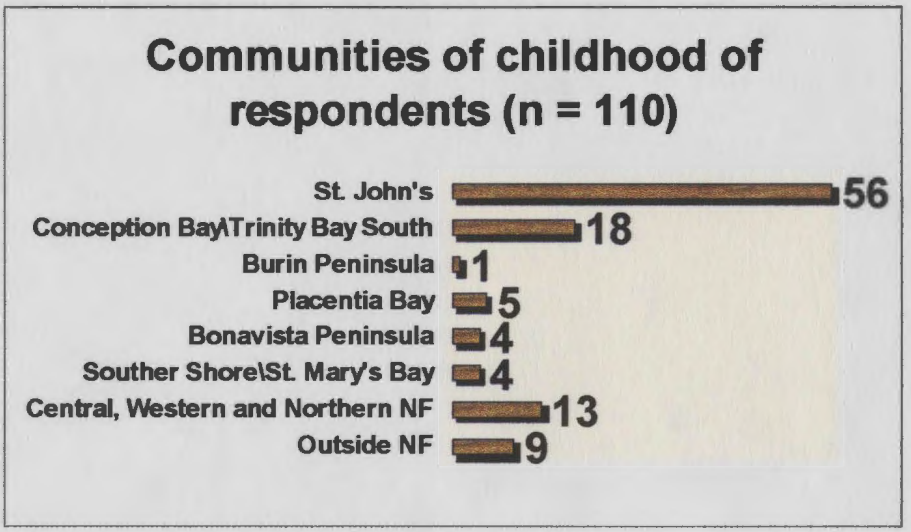
The catchment area for the dermatologists' clinic is eastern Newfoundland including the Avalon, Bonavista and Burin peninsulas (Figure 4) which has a total population of 318,494 or ~60% of the total provincial population of 538,823.

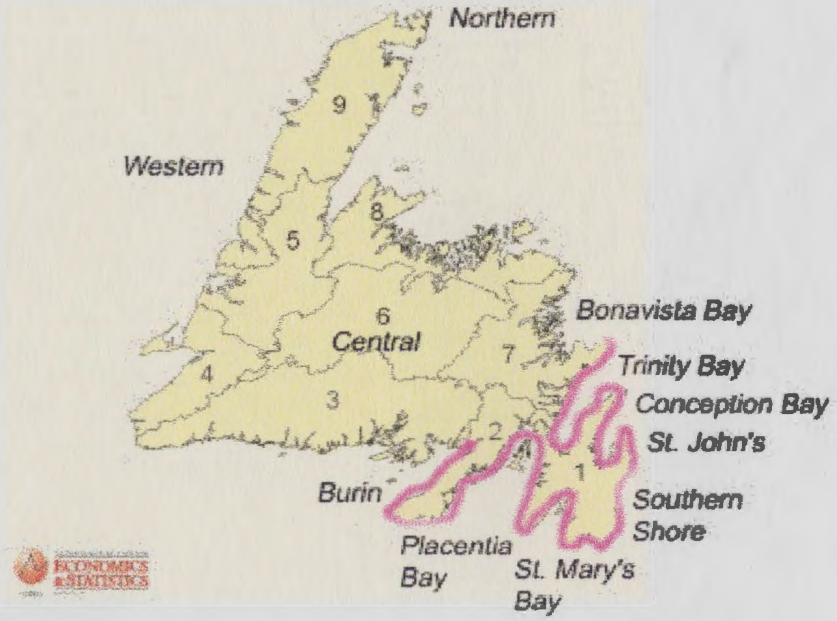
Figure 4. Catchment area



The next figure, Figure 5, shows the respondent's community of childhood.

Figure 5. Respondent's community of childhood





These results of community of origin of the 110 respondents, show that the majority of respondents (50.9%) are from the metro area of St. John's. Individuals raised in the St. John's area often have their roots in other rural locations of the catchment area. Their family may have migrated to the urban areas for employment opportunities. When the community of origin for each of the respondents parents and grandparents were examined the distribution of community of origin changed.

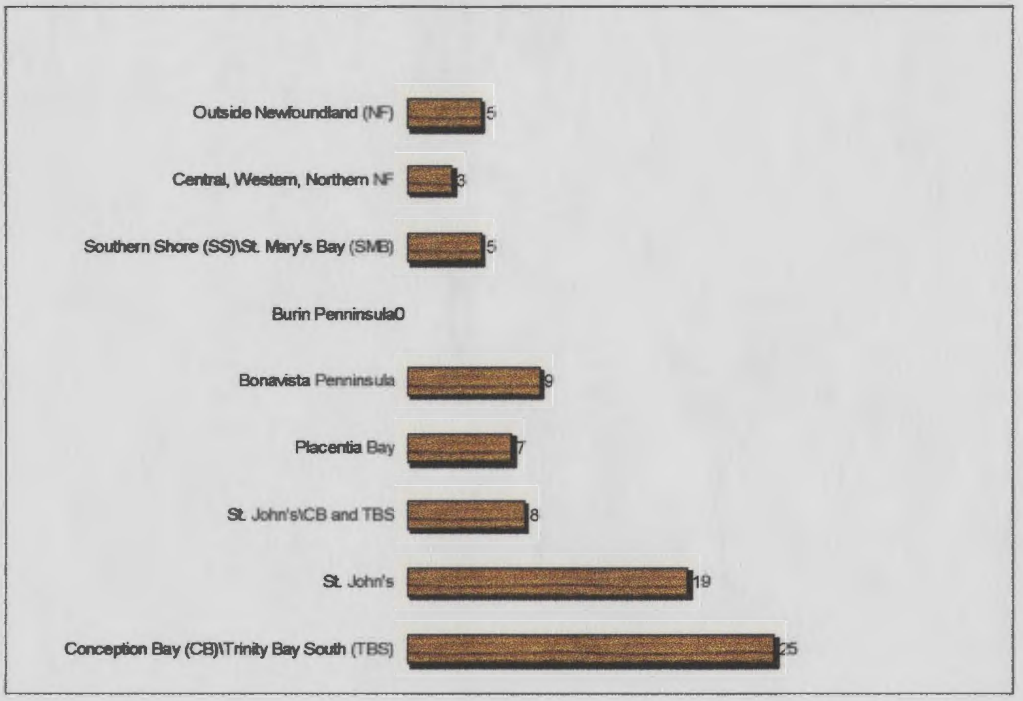
To determine community of origin of parents/paternal & maternal grandparents with accuracy, two groupings were established:

Group 1: Respondents who have/had both paternal and maternal grandparents who come from the *same* general geographic locale (n = 81).

Group 2: Respondents who have/had paternal and maternal grandparents who come from different geographic locales in the province or outside (n = 20) and those who provided no response or unknown community of origin (n = 9).

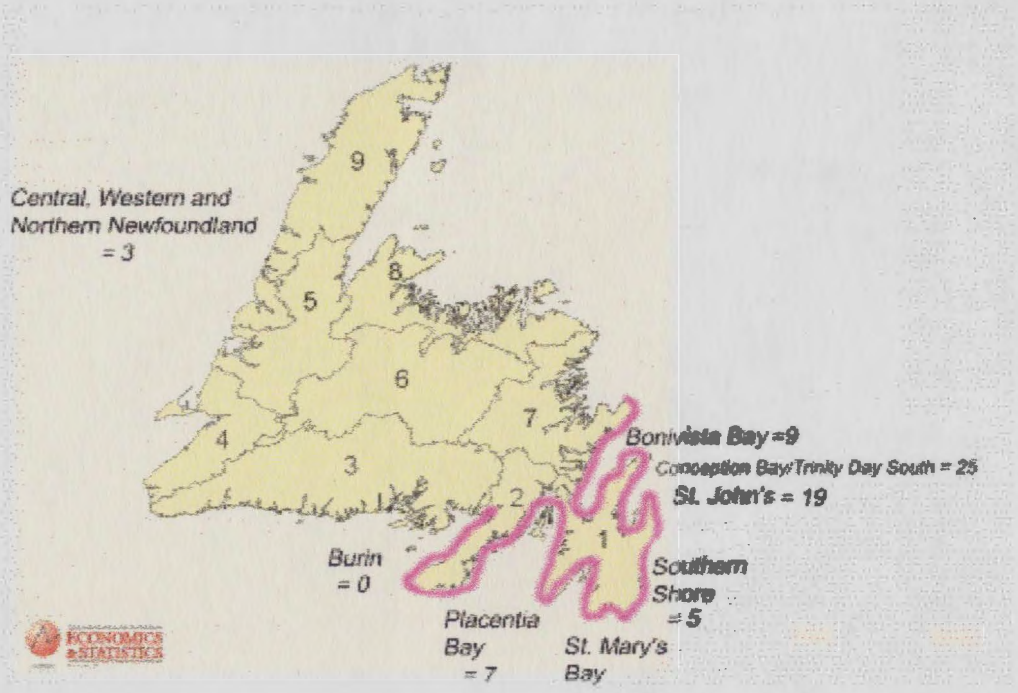
The results that follow address each group. Figure 6 reveals the change in distribution of the community of origin from the majority being from the St. John's metro area to the majority originating in the northwestern side of Conception Bay and the south side of Trinity Bay.

Figure 6. Community of origin geographic distribution when respondent's paternal and maternal grandparents are from the same general locale of the catchment area.



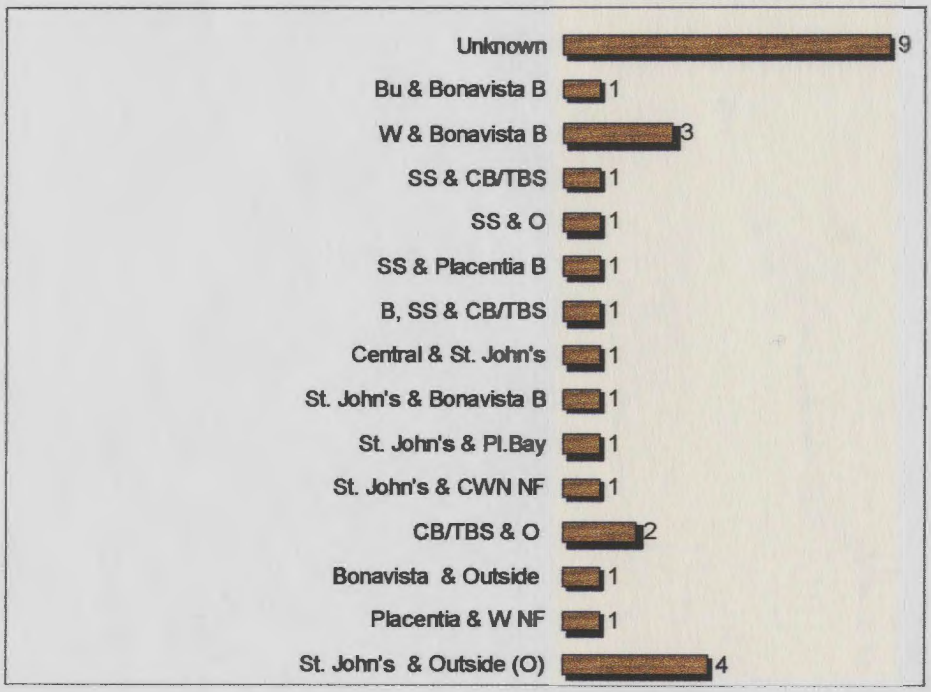
The majority (n=25) are from the northwest side of Conception Bay and Trinity Bay South as indicated below in Figure 7.

Figure 7. Number of respondents with both paternal and maternal grandparents from a specific geographic locale within the catchment area. (n = 81)



The origin of the parents and paternal/maternal grandparents of the remaining 29 respondents (Group 2) are shown in Figure 8.

Figure 8. Community of Origin for respondents with paternal and maternal grandparents from mixed geographic locales. (n = 29)



Bu: Burin Peninsula
SS: Southern Shore and St Mary's Bay
CWN: Central, Western and Northern NF
B: Bonavista Peninsula
O: Outside NF

The number of respondents with rosacea having family roots in the following areas of the Avalon Peninsula was examined in light of the population density of each area.

(i) Conception Bay/Trinity Bay South

(ii) St. John's metro area

There were twenty-five respondents who had paternal and maternal grandparents from one specific area of the Avalon peninsula with a population of ~44,000 . This was compared with the 19 respondents reporting paternal and maternal grandparents from the St. John's area population ~ 174,000. The ratios are given in Figure 9.

Figure 9. Ratio of Cases to Population

Source: Newfoundland Statistics Agency 1996 - 2000 Population Data

5.2 Family Names

One hundred and ten respondents provided the family names of up to four ancestors, father, mother, paternal grandmother and maternal grandmother. The data was analyzed in three ways:

(i) frequency of the names for the 110 respondents,

(ii) frequency of the names of the respondents *and* the maiden names of the respondent's mother, paternal and maternal grandmothers, and.

(iii) the geographic distribution of the frequently occurring family names.

Frequency of Respondent's Names

Of 110 respondents twelve family names occurred more than once or were repeated. One name occurred four times another occurred three times and the remaining each occurred twice.

Frequency of the Names of Respondents and the Maiden names of Mother, Paternal and Maternal Grandmothers.

Up to 440 family names of the mother and the paternal and maternal grandmothers could have been provided but 61 names were unknown or left blank. The actual number obtained was 379.

When the 379 names were examined for frequency the following was revealed: 269 names occurred only once, 30 family names occurred twice, 6 names each occurred four times, 4 names occurred three times and two names occurred seven times. All of those that occur more than once there were a total of 110 names from 379 possibilities or 29.0%.

Table 8. Numerical distribution of family names of parents and grandparents of respondents.

Numerical occurrence of Names (N = 379)	N	%
Names that occurred once	269	71.0
Names that occurred twice	30 (n = 60)	15.8
Names that occurred three times	4 (n =12)	3.2
Names that occurred four times	6 (n = 24)	6.3
Names that occurred seven times	2 (n =14)	3.7
	379	100

Names that occur more than once in 110 respondents

Seventy-one respondents (64.5%) had one or more of these 42 re-occurring family names in their family tree. Thirty-nine respondents had no repeating names in their family tree. Of those who had names in their family tree from among the group of names that occurred more than once, some had more than one and one had to four.

Family Names of Conception Bay and Trinity Bay South

The family names of respondents from Conception Bay and Trinity Bay South were examined. In this group of 25 respondents there were a possible 100 names deriving from the father, mother's maiden name and maiden names of the paternal and maternal grandmothers but the respondents reported only eighty-eight of these names. From this group of eighty-eight names there were a total thirteen family names that occurred more than once. One family name occurred four times in this group of twenty-five, three family names occurred three times and nine family names occurred twice. Table 9 shows the number of respondents from northwest side of Conception Bay and Trinity Bay South with these names among the names of their parents and grandparents.

Table 9. Number of individuals with repeating names in families of 25 respondents from northwest side of Conception Bay and Trinity Bay South

Number of repeated names in respondent's family	N	%
0	6	24.0
1	11	44.0
2	4	16.0
3	4	
Total	25	100.0

Table 10 shows the number of respondents from the remainder of the catchment area with repeating names among the names of their parents and grandparents.

Table 10. Number of individuals with repeating names in families of 85 respondents from the remaining catchment area.

Number of repeated names in family	N	%
0	44	50.0
1	25	28.4
2	15	17.0
3	3	3.4
4	1	1.1
Total	88	100

Further examination of the family tree of respondents is necessary to determine if those with repeating family names have a familial relationship to one another.

Part B - Minor study Objectives

5.5 Sun Exposure

The questionnaire gathered additional information to add to the body of knowledge about rosacea and examined history of sun exposure. Data was collected regarding information on place of work, use of sunscreen and history of sun burn. The data reported in Tables 11 to 14 provides information on this area.

Table 11. Locale of occupational work

Locale	Percent (%)
Indoors	93.0
Outdoors.	7.0
	Range of time: 8 - 44 years

5.5.1 Use of sun screen

Use of sun screen in childhood was low. Its use increased throughout the life cycle with a reported use in adulthood of almost 80% of respondents. Table 12 shows the changes in sun screen usage patterns. Sun screen number 15+ is the most commonly used by 57.8% of the respondents.

Table 12. Reported use of sun screen by patients throughout the life cycle

Childhood	Adolescence	Adults
23.6%	49.1%	79.1%

5.5.2 Skin Type and History of Sunburns

The majority (>80%) of subjects were fair skinned and of a skin type that burns in varying degrees. Only a minority (15.4%) reported that they tanned well and burned minimally. Table 13 shows the breakdown of respondents who self reported skin type.

Table 13. Skin type

	Skin Type	N	% of Patients
I	Always burns, never tans	20	18.2
II	Always burns, tans minimally	29	26.4
III	Burns moderately, tans gradually	41	37.3
IV	Burns minimally, tans well	15	13.6
V	Rarely burns, tans profusely	2	1.8
	No answer	3	2.7
		110	100

Source of classification: Lane, Alfred. "Physical Injury." Pediatric Dermatology, Volume 2 Lawrence A. Schachner and Ronald C. Hansen. New York: Churchill Livingstone, 1988, 1620.

The respondents provided data regarding their experiences with sun burns during childhood. The majority of respondents reported experiencing a form of sun burn that resulted in redness with peeling and redness without peeling. Table 14 shows that a quarter of those who answered this question reported having blistering sunburns in

childhood that did not require medical attention; a very small minority experienced serious sunburn requiring medical attention (4.6%).

Table 14. History of serious sun burn in childhood

Type of sunburn	N	Percent (%)
Blistering sun burns requiring medical attention	5	4.6
Blistering sun burns not requiring medical attention	27	24.7

5.6 Frequency and severity of triggers

The frequency and severity of the triggers coincided with reports of triggers in text books, medical literature and educational materials. The strongest and most frequent trigger was stress followed by extremes in temperature , red wine and spicy food. The respondents were asked to identify items or events that trigger a flare up of rosacea other than those listed in the questionnaire. Table 15 lists the responses given by 20 patients. Twenty patients (18.1%) responded. Make up, menstruation, and swimming in chlorinated water were each reported by two respondents and the remainder were reported only once.

Table 15. Uncommon Triggers reported by respondents

Trigger	N
red ju jubes	1
licorice	1
make up	2
menstruation	2
animated conversation	1
swimming and chlorinated water	2
air travel	1
dust	1
pregnancy	1
ultra violet lights,	1
vinegar,	1
yoghurt	1
sour cream,	1
scents and smells,	1
high humidity,	1
gravy	1

5.7 Quality of Life

Due to the fact that rosacea is manifested by an alteration to the normal epidermis of the face, it has the potential to have a psychological impact on the individual with this disease. The data reveals how respondents in this population feel in two time periods (over the past week and over the past year) and covers how rosacea affects their lifestyle.

Rosacea is a cause for discomfort when interacting in social relationships. Table 16 shows that a majority of patients with rosacea have experienced discomfort in the last year while social interacting due to rosacea. It was also the cause for interference in activities by a third of the respondents.

Table 16. Effects of Rosacea on lifestyle

Impact of rosacea upon the individual	**N**	**Last week %**	**N**	**Last year %**
General reaction				
Affected a little	26	23.6	47	42.7
Embarrassed by rosacea	20	41.8	31	70.9
Specific activity				
Prevented from eating or drinking at a social event	23	20.9	40	36.3
Prevented participation in an outdoor activity	*25*	22.7	35	31.8
Negative effect on sexual relationship	4	3.6	11	10.0

Respondents reported that meeting strangers has the strongest effect upon individuals with rosacea. As Table 17 shows, the more distant the relationship the more uncomfortable they felt.

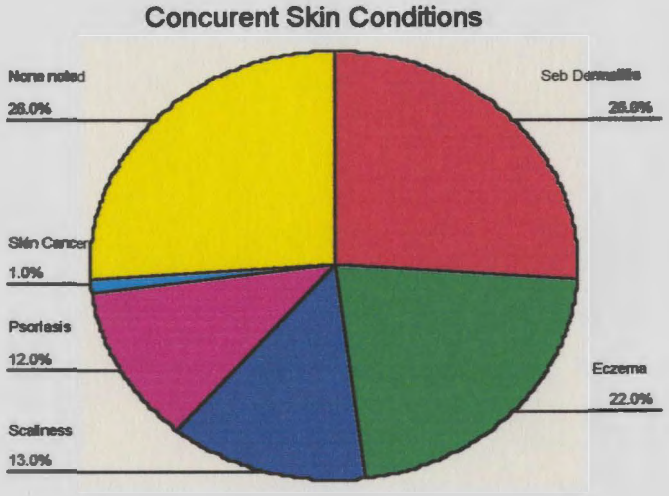
Table 17. Patients reporting discomfort in relationships due to rosacea

Relationship with	N	Percent (%)
Siblings	5	5.7
Friends	20	22.2
Co-workers	20	22.2
Partner	6	3.9
Strangers	30	32.3

5.8 Other Skin Conditions

Figure 10 shows that concurrent skin conditions are experienced by approximately one quarter of population under study. Seborrheic dermatitis (dandruff) was the most commonly reported (26%), followed by eczema (22.0%). The other skin conditions that were examined included scaliness around the nose and chest, psoriasis, and skin cancer (both benign and malignant) were less commonly reported.

Figure 10. Concurrent skin conditions of respondents with diagnosed rosacea.



5.8.1 Respondents with rosacea with more than one concurrent skin condition

A small minority of patients (7.1%) with rosacea have *more than* one concurrent skin condition. Five patients or 5.1% had rosacea, seborrehic dermatitis and scaliness around the nose and centre of the chest; two patients (2.0%) had rosacea, psoriasis and eczema. One patient had rosacea, plus four other skin conditions: psoriasis, eczema, seborrehic dermatitis and scaliness around the nose and centre of the chest.

5.8.2 Family members of respondents with other skin conditions

It was found that 52.7% of families members of respondents have one or more other skin conditions with the largest number having eczema.

CHAPTER VI – DISCUSSION

6.1 Limitations of the Study

The study was limited to *diagnosed* rosacea patients in a particular geographic locale of the province. Limitations included the following:

Defined Population:

In the absence of a registry of rosacea it was not possible to identify a complete rosacea population and hence obtain a probability sample. The creation of such a registry is underway and it would be interesting to examine family history and community of origin once a sufficiently large number of cases have been recorded.

Response Error/ Recall Bias:

Family history recall was limited due to deaths and limited family contact. The history of sun exposure and quantitative information on history of sun burn required checking and recall of those in the pilot group to determine if the answers to these questions was reliable. Contacting those by telephone proved to be difficult and once again this proved to be a limitation regarding the collection of data for these variables. Out of 22 contacts made, only 18 were at the telephone number in the clinic records. The follow up calls met with limited success, with only 13 responses.

Non response error:

There were limitations obtaining family names and communities of origin for all respondents due to recall difficulties that were encountered when respondents did not have family name information for paternal and/or maternal grandparents.

Non returns:

The success in obtaining information from all who agreed to participate was limited by those who agreed to participate and signed consent forms but did not return the questionnaire. A higher percentage of returns would have been realized if the patients completed the questionnaire on site prior to leaving the clinic. Unfortunately, it was not possible for all patients to stay in the clinic to complete the questionnaire due to family members waiting outside or other reasons which prevented them from remaining.

Confidentiality and Family Names:

Confidentiality in the use of family names limits what can be reported. However, it will not limit the ability to proceed to a further research project to determine specific genetic involvement.

Accuracy in reporting:

The reporting of those who had family members with *diagnosed* rosacea as opposed to those family members who exhibited signs and symptoms of roscaea limited the data's absoluteness. Diagnosis of family members by a clinician is required to conclusively report the family history.

6.2 Discussion of Results

6.2.1 Family History

The results strongly indicated that there is a strong family history of rosacea in this group of respondents. The main objective of this study was to review the frequency of family history in a diagnosed group of rosacea patients. Sixty-seven percent of

respondents, or 74 of 110, patients reported that they have family members with signs and symptoms of rosacea and of these, seventy-four percent had two or more (2 to16) family members. Some families report its presence in four generations. Family history has not been broadly reported in medical research papers and when it has been noted, it is in a broad range from 5 to 40%.[5,8,9,18,26,54] Objective epidemiological research on this variable is limited. Therefore, as there are few references in the literature, this information will be of interest to clinicians and will support that which is currently reported. Such data is important in that it can form the foundation for future research to investigate the possibility of genetic etiology of this skin disease. The data obtained from this particular study can be utilized by future researchers to begin a search for a susceptibility gene for rosacea. The data will provide a starting point for pedigree analysis of these individuals in order to determine the appropriate method to approach linkage analysis, linkage disequilibrium analysis or other methods of analysis.

6.2.2 Community of Origin

The respondents in this study provided data about a group who live in a distinct catchment area with common origins. One geographical locale of the catchment area, the northwest side of Conception Bay and Trinity Bay South had a higher number of cases (25) of patients with rosacea having *both* paternal and maternal roots in this area of relatively low population: 44,000 (1:1,760) compared to 19 in the metro region, with a population of 224,000 (1:11,789). The common names and inter-relatedness of the people in Conception Bay\TrinityBay South area provides a starting point to explore the

probability of the disease passing from one generation to the other. It provides added support for a possible genetic origin for rosacea.

The respondents in this less densely populated area is of interest to future researchers who may wish to explore the entry point of a genetic linked disease. By noting the distribution of this group of diagnosed rosacea patients, one may be able to trace the origins of people in this area to a particular area of ancestry in south-west England. The literature states that those with rosacea are of northern European ancestry. Examination of the roots of this group, known to be from southwest England, may help narrow this group to a specific northern European grouping such as Goydelic or Brythonic Celts.

6.2.3 Demographics

The group reflects the profile of other populations and samples of rosacea in age. They are on average generally in their mid forties. Some were diagnosed as early as twenty and others in their seventies. The male to female gender ratio is in keeping with that which is commonly reported.[2,4,11,12,20] The 1989 Swedish study conducted by Berg and Liden closely resembled the demographic profile for these common variables, i.e. age and gender.[20]

The physical characteristics of respondents are of interest simply because they provide pause for thought. Eye colour and hair colour have not been reported in the literature in the specific manner they are here. While the eye colour for the large majority of respondents is recessive (blue and green/hazel), the hair colour of respondents does not include a great number of blondes or redheads. The very fair skinned person is not

predominant, rather it is the medium to fair skinned individual. The recessive eye colour that is exhibited in the majority of patients is of interest and poses questions regarding an association with the genetic basis for this disease.

Reports in the literature regarding the appearance of symptoms of the disease and confirmation of diagnosis and menopausal status is similar. Although the gender distribution for the respondents is 3:1, it is curious to note that *male parents* with rosacea outnumber the *female parents* (25% and 18%). This may be due to recall bias.

6.2.4 Sun Exposure

The data collected on history of sun exposure was generally unremarkable. The majority of respondents conducted their occupational pursuits inside rather than out of doors. The respondents provided little data on history of sun burn due to recall limitations. This area of study would make an interesting future study, however, it would be useful to ask questions that required general responses rather than either yes or no which is limiting due to inaccurate recall. The Skin Type provided information about the *likelihood* of skin to burn, yet the data on the number of severe sun burns was limited.

6.2.5 Frequency and Severity of Triggers

Stress was reported as the number one trigger in both frequency of occurrence and severity once it does occur. This is in keeping with the reports in textbooks and educational literature.

6.2.6 Quality of Life

The study generated data on the human experience in the natural setting of those with this disease. The questionnaires did not ask respondents how they felt regarding

self-esteem but rather asked if they were embarrassed by rosacea or if it affected them in relationships or activities. The results of the data indicate that the disease has an effect on the individual, with the majority reporting that they felt embarrassed by rosacea in the last year. While this does not provide immediate conclusions or outcomes for practice, it does provide additional knowledge about quality of life impact for those with a particular skin disease adding to the literature and anecdotal information pertaining to the psycho-social experience and effect of facial dermatological conditions. This indicates that the need for early diagnosis and treatment is not only to relieve physical symptoms and discomfort but also to provide relief from embarrassment.

6.2.7 Other Skin Conditions

A small majority of respondents (52.7%) report that they have family members with other skin conditions. Approximately 1/4 of the respondents family members also have eczema, and seborrehic dermatitis. These results are unremarkable, but provide information for future research on the topic of concurrent skin conditions.

SUMMARY

The data provided from this descriptive survey of participants with diagnosed rosacea provides a good description of a number of elements encountered in the human experience of an individual with rosacea. It should be of interest to medical professionals for a number of reasons. First, due to the absence of solid information in the literature about family history and the absence of a cause of rosacea, the identification of a population with this disease through name and community of origin adds to the current knowledge about this disease and provides the basis for future genetic research. The current knowledge of family history is limited due to the absence of objective data. Anecdotal and clinical evidence form the basis of what is known concerning family history. The few reports that are in the literature give a wide range with figures from 5 to 40%. The data from this research study provides additional knowledge to that which is currently available in medical literature.

Furthermore, the identification of patients with a range of family history from 0 to 16 family members is valuable. The group of individuals, notably those who have multiple family members with signs and symptoms or diagnosed rosacea, can form a group of possible research subjects for future investigation of genetic etiology of rosacea.

Secondly, this knowledge can be utilized in medical practice in the following areas:

(i) Early intervention

Awareness by family physicians that a genetic predisposition may assist in diagnosis and early intervention. Early intervention as a preventative measure in the first

instance of those with fair skinned offspring and patient education as to the importance of avoidance of extreme or long-term sun exposure may delay the onset of this disease.

(ii) Potential for new drug development

The discovery of a gene that controls the inflammatory response characteristic of roscaea may lead to the development of a drug that could be utilized to target inflammation especially around the oil glands. New drug therapies may emerge for treatment based upon genetic identification.

(iii) Diagnosis criteria

Diagnosis criteria or risk factors have not been established. This data may assist the diagnostician in identifying susceptible family members using the criteria of recessive eye color, family history, and hair colour.

(iv) Awareness of likelihood of concurrent skin conditions and combination treatment.

Physicians aware of concurrent skin conditions, especially seborrehic dermatitis, may select a combination of two active ingredients in the treatment of more than one skin disease.

(v) The education of families with this disease.

The fact that rosacea may be an inherited disease will focus attention on avoidance of known triggers for those who are family members and offspring of an individual with rosacea.

The data reveals that this disease has a negative impact upon those who have it.

The strong family history data should prompt physicians to identify those with a possible predisposition to develop rosacea. Education, early intervention and treatment are necessary in order to avoid the potential negative social impact of this disease. Identification of a particular population with a strong family history leading to further research in the area of genetic etiology is a progression in the evolution of the knowledge and treatment of rosacea. The spinoffs of genetic identification, including a pharmaceutical treatment to provide long-term resolution of the symptoms of rosacea, would be welcomed by those who experience both the psycho-social and physical discomfort and limitations brought on by this disease.

Conclusions

This study provided solid results on the main study objective (to determine if there is a family history of rosacea) and secondly allowed the determination of an association with family name and community of origin. The evidence of a strong family history of rosacea in respondents supports the anecdotal and clinical evidence of a genetic predisposition of this disease. It adds to the current knowledge in the literature that there is a family history and it provides data that supports the possibility of a genetic factor, as evidenced by its appearance in up to four generations.

The identification of specific individuals through family name and community of origin in a specific geographic locale of the catchment area provides valuable information for researchers choosing to delve further into a study of genetic etiology of rosacea.

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Information Regarding Rosacea Research Study

I invite you to participate in a rosacea research study that is presently ongoing. If you wish to volunteer to take part in this study, you will be given a questionnaire that will take approximately 15 minutes to complete. Should you begin the questionnaire and do not wish to continue it, you may withdraw from the study at any time and it will not impact upon your normal treatment.

The purpose of this research is to see if there is a family trait that leads to the development of rosacea. The study will look at family history, skin type, the amount of sun that you have been exposed to and the effect that having rosacea has on your life.

The study will involve the person who has rosacea or any other person who assists you in answering the questionnaire. You will be asked to complete this questionnaire on one occasion only. It can be completed at home or in the doctor's office. If you require help with this questionnaire, you can call me, the researcher.

If you decide not to enter the study, you will not jeopardize your normal treatment.

If you have any questions, please feel free to speak with your dermatologist, his research assistant or with the researcher named below.
Thank-you for your time and cooperation.

Donna Fagan
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PATIENT INFORMATION AND CONSENT FORM

TITLE: **Factors in the Development of Rosacea**

SPONSOR: **Galderma**

INVESTIGATOR: **Donna M. Fagan, Graduate Student, Faculty of Medicine**

SUPERVISORS: **Dr. Nigel Rawson, Community Health, Faculty of Medicine**
Dr. Wayne P. Gulliver, Dermatologist

You (or your child or ward) have been asked to participate in a research study. Participation in this study is entirely voluntary. You may decide not to participate or may withdraw from the study at any time without affecting your normal treatment or your relationship with your physician.

PURPOSE OF THE STUDY:

The purpose of this research is to determine if there is a family trait that leads to the development of rosacea. The study will look at family history, skin type, the amount of sun that you have been exposed to and the effect that having rosacea has on your life.

DESCRIPTION OF PROCEDURES:

All participants will be asked to complete a questionnaire that will take approximately 15 minutes.

DURATION OF PARTICIPANTS INVOLVEMENT:

This study requires a one-time involvement of completion of the questionnaire. If the participant would like assistance in answering any of the questions, the investigator, the dermatologist or his research assistant will be available to do so and may be contacted by calling the dermatologist's office.

FORESEEABLE RISKS, DISCOMFORTS, OR INCONVENIENCES:

There are no foreseeable risks, discomforts or inconveniences anticipated to be experienced by those participants who complete the questionnaire.

Patient's Initials: _____

NewLab Clinical Research Inc.
Dr. WAYNE P. GULLIVER, MD, FRCPC
1 Anderson Avenue
St. John's, NF A1B 3E1

Telephone:(709) 753-5522
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ALTERNATIVE TREATMENTS FOR THOSE NOT ENTERING THE STUDY:

There are no treatments involved with this study, and if you are currently being treated by the dermatologist, you will continue with your normal treatment.

LIABILITY PARTICIPATION:

Your signature indicates your consent and that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive you legal rights nor release the investigators, sponsors or involved institutions from their legal and professional responsibilities.

FINANCIAL BENEFIT:

There is no financial benefit for the graduate student as a result of this research.

CONFIDENTIALITY:

Confidentiality of information concerning participants will be maintained by the investigator and the study staff. You will be identified only by an **identification number** to protect your privacy. At no time, will any publication resutling from this study contain any information that could identify you.

If at any time you wish to withdraw from this study, you may request to have your questionnaire with your answers removed by notifying the dermatologists office or study staff.

Patient's Initials:_____

SIGNATURE PAGE

I, _____ the undersigned, agree to my participation or to the participation of _____(my child, ward, relative) in the research study described.

Any questions have been answered and I understand what is involved in the study. I realize that participation is voluntary and that there is no guarantee that I will benefit from my involvement. I acknowledge that a copy of this form has been given to me.

_____ _____

Signature of Participant Date

_____ _____

Signature of Witness Date

TO BE SIGNED BY INVESTIGATOR

To the best of my ability I have fully explained to the subject the nature of this research study. I have invited questions and provided answers. I believe that the subject fully understands the implications and voluntary nature of the study.

_____ _____

Signature of Investigator (Donna Fagan) Date

_____ _____

Signature of Supervisor (Dr. Wayne Gulliver) Date

Telephone: (709) 753-5522

If required:

_____ _____

Signature of Minor Participant Date

Age:

For office use only: A ☐ B ☐ C ☐ D ☐ E ☐ F ☐ ID #

Rosacea Questionnaire

SECTION A - DEMOGRAPHIC INFORMATION

1. GENDER

01 Male ☐
02 Female ☐

2. AGE (years)

How old are you?_____

_____

3. HAIR COLOUR

01 Black ☐
02 Dark Brown ☐
03 Light Brown ☐
04 Blonde ☐
05 Auburn ☐
06 Red ☐

4. EYE COLOUR

01 Blue ☐ 02 Brown ☐

03 Green/Hazel ☐ 04 Grey ☐

5. DIAGNOSIS

At what age were you diagnosed with rosacea?

_____

6. How long have you had rosacea?

_____

7. For females only: were you pre or post menopausal when first diagnosed?

Pre 01 ☐ Post 02 ☐ Menopausal 03

8. What was your last name when you were born?_____

SECTION B: ETHNIC GROUP

9. In what country were you born?

_____

10. Where did you live during your childhood, and for how long?

City/town and country	For how long (yrs)?
1.	
2.	
3.	

11. Where did your father live during his childhood and for how long?

Unknown ☐

City/town and country	For how long (yrs)?
1.	
2.	
3.	

12. Where did your mother live during her childhood and for how long?

Unknown ☐

City/town and country	For how long (yrs)?
1.	
2.	
3.	

SECTION B: ETHNIC GROUP cont'd.

13. Where did your *mother's* mother live during her childhood and for how long?

Unknown ☐

City/town and country	For how long (yrs)?
1.	
2.	
3.	
4.	

14. Where did your *mother's* father live during his childhood and for how long?

Unknown ☐

City/town and country	For how long (yrs)?
1.	
2.	
3.	
4.	

15. Where did your *father's* mother live during her childhood and for how long?

Unknown ☐

City/town and country	For how long (yrs)?
1.	
2.	
3.	
4.	

16. Where did your *father's* father live during his childhood and for how long?

Unknown ☐

City/town and country	For how long (yrs)?
1.	
2.	
3.	
4.	

Give the last name of each of the following relatives: "DO NOT INCLUDE STEP PARENTS OR STEP GRANDPARENTS"	**Last Name (Family name at birth)**	If Unknown (✓)
Example: Father's Mother's last name:	**SMITH**	
17. Father's last name:		
18. Father's mother's last name:		
19. Mother's last name when she was born:		
20. Your mother's mother's last name when she was born:		

What is the ethnic background of your parents and your grandparents? Select from the list below

"DO NOT INCLUDE STEP PARENTS OR GRANDPARENTS"

Example: Your father	Scottish	
RELATIVES	ETHNIC BACKGROUND	If unknown (✓)
21. Your father		
22. Your grandmother (on your **father's** side)		
23. Your grandfather (on your **father's** side)		
24. Your mother		
25. Your grandmother (on your **mother's** side)		
26. Your grandfather (on your **mother's** side)		

English 01 French 04 Norwegian 07

Irish 02 AngloFrench 05 Mic mac08

AngloIrish 03 Scottish 08

If ethnic group not listed, please write it here: _____

SECTION C: HISTORY OF SUN EXPOSURE

Occupation

27. Where do/did you work? Indoors 01 ☐ Outdoors 02 ☐	**28.** If outdoors, then how many **years** did you have this job?	**29.** In this job, how many days a week were spent **outdoors** (approx)?	**30.** How many hours per day were **outdoors** (approx)?
If outdoors list the job: 1. Present:			
2. Previous:			
3. Previous:			

History of Exposure to Sunlight
Circle the number that best describes how often you have used sun screen in each of the following stages of your life.

31. Stage of Life	**1 = never**	**2 = occasionally**	**3 = all the time**
1. Childhood	1	2	3
2. Adolescence	1	2	3
3. Adulthood	1	2	3

32. Are you in the habit of using sun screen when in direct sunlight? Yes:____ No:____ **33.** What sun screen number do or did you use? Circle one below: 15 + , 10 - 15 , 8 - 10 4-8, < 4 or unknown none	**34.** Have you ever used: Yes, No, or Never Tanning beds? _____ Tanning Pills ? _____ Tanning Creams or lotions? _____ Sun Lamps? _____	**35.** When using a sun lamp or tanning beds did you ever experience a sunburn? (✓) Yes____ No____ **36.** How many times have you burned using artificial suntanning methods? _____

Indicate the average time you spend out of doors on weekends for leisure purposes during each of the stages of your life. Please circle the one that best matches your experience.

1= 30 mins/day	**2=** 1 - 2 hrs/day	**3** = 3 -4 hrs/day	**4=** 5-6 hrs/day	**5=** 6hrs+/day

37. Childhood (2-12 yrs)	1	2	3	4	5
38. Adolescence (13-19 yrs)	1	2	3	4	5
39. Adulthood (20 yrs +)	1	2	3	4	5

40. Check the **Skin Type** that most closely applies to you when you are **not** using sun screen.

✓	Skin Type	Sunburn History	Suntan History
	01 I	Always burns	Never tans easily
	02 II	Always burns	Tans minimally
	03 III	Burns moderately	Tans gradually
	04 IV	Burns minimally	Tans well (medium brown)
	05 V	Rarely burns	Tans profusely (dark brown)
	06 VI	Never burns	Deeply pigmented (black)

Indicate how **often** you ever received a burn which... (If you need help, see the following example to assist you in completing this).

Type of Burn	41. In your childhood (2-12 yrs)	42. In your adolescence (13 - 19 yrs)	43. In your adulthood (20+ yrs)
01 was a blistering burn which required medical attention?			
02 was a blistering burn which did not receive medical attention?			
03 had redness/ sensitivity with peeling?			
04 had redness/sensitivity with no peeling?			

SECTION D: TRIGGERS (or events that bring about a rosacea flare up).

44. How often do you experience a flare up of rosacea? (✓)

Weekly _____; Monthly_____; Six times a year_____; Five times a year_____; Four times a year_____;

Three times a year_____; Twice a year_____; once a year_____

Next to each trigger, listed below, select the number that best suits your experience of both the **frequency** and **severity** for each one.

Trigger	**Frequency** 0 = Never; 1 = Yearly; 2 = Monthly 3 = Weekly 4 = Daily 5 = Always N/A = Not applicable	**Severity** 0 = never 1= mild; 2 = Moderate; 3= Strong; 4 = Severe N/A = Not applicable
Example :Cold weather	2	1
45. Hot weather		
46. Cold weather		
47. Sunlight		
48. Extreme changes in temperature		
49. Red wine		
50. White wine		
51. Beer		
52. Hard liquor		
53. Hot spicy food		
54. Tea		
55. Coffee		
56. Stress		
57. Video terminals/computers		
58. Strenuous Exercise		

59. Do you experience other triggers that are not listed above? Yes ☐ No ☐

If Yes, please state what else is a trigger for you and indicate the frequency and severity of it. You may use the above numbers in your answers.

Trigger_____ Frequency:_____ Severity_____

SECTION E: LIFESTYLE (Quality of Life)

Indicate if rosacea affected your participation in any of the following activities last week and/ or last year. Choose from the following numbers to indicate how rosacea affected you in each case.

0 = Not affected 1 = Affected a little 2 = Extremely affected

The Activity	Last week	Last year
Example: Have you been embarrassed or self conscious because of rosacea?	0	1
60. Have you been embarrassed or self conscious because of rosacea?		
61. Has rosacea interfered with your going shopping or to entertainment or other public places?		
62. Did you not attend a social event or leisure activities due to rosacea?		
63. Has rosacea had a negative effect on your sexual relationship with others?		
64. Has rosacea prevented you from participating in eating or drinking at a social event?		
65. Has rosacea prevented you from attending an exercise program?		
66. Has rosacea prevented you from participating in an outdoor activity?		
67. Has rosacea prevented you from using a computer or video terminal?		
68. Has rosacea interfered with your relationship with others?		
69. If rosacea affects your relationship with others, please circle as many as apply. Parent Sibling Friends Coworkers Partner Strangers		

Are there any other activities that rosacea has prevented you from participating in?

_____

_____

SECTION F: FAMILY HISTORY

This section refers to your biological parents. Please answer Yes, No or Unknown to the following questions

RELATIVE	Does/did he or she have rosacea? Please state: Yes, No or unknown...	If he/she has/had rosacea, has it been diagnosed by a doctor?	Has he/she NOT been diagnosed but has the signs and symptoms?	Does he/she have stomach problems? Yes or No, if possible, please specify.
70. Mother				
71. Father				

This section refers to your children and your brothers and sisters. Do not include step and adopted children; or step and adopted sisters and brothers.

RELATIVE	How many do you have?	How many have rosacea?	If they have rosacea, how many have been diagnosed by a doctor?	If they have rosacea, how many are NOT diagnosed but have the signs and symptoms?
72. Brothers				
73. Sisters				
74. Female Children				
75. Male Children				

This section refers to your **aunts and uncles on your mother's side.**

RELATIVE	How many do you have?	How many have rosacea?	If they have rosacea, how many have been diagnosed by a doctor?	If they have rosacea, how many are NOT diagnosed but have the signs and symptoms?
76. Aunts				
77. Uncles				

This section refers to your **grandparents** on your **mother's side.**

RELATIVE	Does he/she have rosacea?	If he/she has rosacea, has it been diagnosed by a doctor?	If he/she has rosacea, do they have the signs and symptoms but are not diagnosed?
78. Grandmother			
79. Grandfather			

This section refers to your **aunts and uncles** on your **father's side.**

RELATIVE	How many do you have?	How many have rosacea?	If they have rosacea, how many have been diagnosed by a doctor?	If they have rosacea, how many are NOT diagnosed but have the signs and symptoms?
80. Aunts				
81. Uncles				

This section refers to your **grandparents** your **father's side.**

RELATIVE	Does he/she have rosacea?	If he/she has rosacea, has it been diagnosed by a doctor?	If he/she has rosacea, do they have the signs and symptoms but are not diagnosed?
82. Grandfather			
83. Grandmother			

This section refers to the **children** of your **father's brothers and sisters (your cousins).**

RELATIVE	How many do you have?	How many have rosacea?	If they have rosacea, how many have been diagnosed by a doctor?	If they have rosacea, how many are NOT diagnosed but have the signs and symptoms?
84. Male cousins				
85. Female cousins				

This section refers to the **children** of your **mother's brothers and sisters (your cousins).**

RELATIVE	How many do you have?	How many have rosacea?	If they have rosacea, how many have been diagnosed by a doctor?	If they have rosacea, how many are NOT diagnosed but have the signs and symptoms?
86. Male cousins				
87. Female cousins				

SECTION F: OTHER SKIN CONDITIONS or TRAUMA

88. Please complete the following chart noting if you or any of your family members have one or more of the skin problems on this list.

Family member with a skin problem	# with Psoriasis	# with skin cancer (both pre and malignant) please indicate which	# with Dandruff (seborrheic dermatitis)	# with exema	# with scaliness around nose or centre of chest.
You	#	#	#	#	#
Child	#	#	#	#	#
Brother	#	#	#	#	#
Sister	#	#	#	#	#
Mother	#	#	#	#	#
Father	#	#	#	#	#
Aunt on mother's side	#	#	#	#	#
Uncle on mother's side	#	#	#	#	#
Cousins on mother's side	#	#	#	#	#
Grandmother on mother's side	#	#	#	#	#
Grandfather on mother's side	#	#	#	#	#
Aunt on father's side	#	#	#	#	#
Uncle on father's side	#	#	#	#	#
Cousins on father's	#	#	#	#	#
Grandmother on father's side	#	#	#	#	#
Grandfather on father's	#	#	#	#	#

89. Did you experience a physical trauma within approximately six months prior to the onset of symptoms of rosacea?

Yes ☐ No ☐
Please explain_____

90. Did you experience an emotional trauma within approximately six months prior to the onset of the symptoms of rosacea?

Yes ☐ No ☐
Please explain_____

THANK-YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE