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Access Pathway Delays and Burden of Disease for Patients with Severe Chronic Skin Conditions Requiring Systemic and Biologic Therapies at an Irish Dermatology Centre

Alani A*, Sadlier M, Uddin A, Hackett C, Ahmad K and Ramsay B

Department of Dermatology, University Hospital Limerick, Ireland

*Corresponding author: Alani A, Department of Dermatology, University Hospital Limerick, Ireland, Tel: 447490192716; E-mail: angelaalani@yahoo.com

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Abstract

Diseases that directly affect the skin are the fourth most frequent cause of all human illnesses. Despite this, skin diseases continue to receive little attention. Dermatology waiting times in Ireland are longer when compared to other health systems abroad. In this study we highlight a cohort of dermatological patients with inflammatory skin conditions, that require attention with regards to access to dermatological services.

Aim of this study was to analyse our patient cohort currently taking biologic therapy to determine how they accessed the hospital system and the time course of transition to systemic and biologics therapy. This was a retrospective study with analysis of patients on biologic agents: etanercept, adalimumab, ustekinumab, infliximab and golimumab for chronic dermatoses from 2006-2012. We identified 157 patients on biologics between this period, with 114 of these patients currently on biologic therapy. Although 55% (62) were seen within 6 months of referral the mean wait from receipt of a GP referral letter to being seen in the outpatient was 11.6 months (range 0-87 months).

This study shows that patients with severe inflammatory skin disease face significant delays in accessing the hospital system. This is partly due to inadequate infrastructure and staffing of Dermatology units.

Keywords: Dermatology; Biologic therapy; Neoplasia

Introduction

Diseases that directly affect the skin are the fourth most frequent cause of all human illnesses. They affect 1.9 billion people at any time, despite this, skin diseases continue to receive little attention in national and international health debates [1].

As the skin is the largest organ in the body, disease can manifest itself through a range of physical or mental incapacity and even death and it is the leading reason for seeking medical attention across all cultures and societies [2,3].

Dermatology waiting times in Ireland are longer when compared to other health systems abroad. Waiting times for a dermatology appointment were ranked as fourth on the national outpatient waiting lists in 2012, waiting in excess of one year for an outpatient dermatology appointment, after other specialities such as orthopaedics, ENT and general surgery [4-6].

While the National cancer registry, has reported that melanoma is the ninth most common cancer in Ireland, accounting for 2.4% of all malignant neoplasia in men and 4.2% in women.

The Irish cancer society has identified non-melanoma skin cancer to be the most common cancer. In 2009 alone, 8145 new cases were reported. Incidence of melanoma rates are rising annually, according to the 2010 National Cancer Registry of Ireland report, between 1998 and 2008, melanoma rates have increased 91% (from 393 cases in 1998 to 752 in 2008). Skin cancer such as melanoma can be devastating and the recent National Cancer Control Programme (NCCP), has focused much attention on the importance of early melanoma diagnosis and treatment. This has resulted in the establishment of pigmented lesion clinics in many dermatology units in Ireland to expedite a rapid review of all suspicious pigmented lesions.

In this study we highlight a further cohort of patients those with inflammatory skin conditions as a subset of dermatological patients that require attention with regard to access to dermatological services and requirement for structured ongoing care.

Aim

The aim of this study was to analyse our patient cohort currently taking biologic therapy to determine how they accessed the hospital system and the time course to transition

from their initial presentation through to systemic and biologics therapy.

Methods

This was a retrospective study with analysis of charts of all patients on biologic agents: etanercept, adalimumab, ustekinumab, infliximab and golimumab for chronic dermatoses from 2006 to 2012.

Data collected included demographics, interval between General Practitioner (GP) referral to Hospital and being seen by a dermatologist, introduction of systemic treatment to commencement of biologics. Initial data was extracted by FileMakerProvs12 which was later transferred to excel to analyse it.

We also used data on patients currently taking biologics and used their letters to plot out a profile for each patient.

Results

Our current department database of patient letters contains 36,555 letters from mid 2006 with 3096 letters solely for psoriasis patients. We identified 157 patients on biologics during this period with 114 of these patients currently on biologic therapy. The mean age was 48 years (range 14-84 years) at commencement of biologic; 64 female and 50 male-94 patients with psoriasis, 13 had hidradenitis suppurativa (HS), 5 cutaneous Crohn's Disease and 2 with Behcets Disease.

Although 55% (62) were seen within 6 months of referral the mean wait from receipt of a GP referral letter to being seen in the outpatient was 11.6 months (range 0- 87 months). The majority of patients 66% (75) had one or more co-morbidities (Table 1).

Table 1: Co-morbidities vs. number of patients.

Co-morbidities	Number of patients
Psoriatic arthritis	37
Diabetes	11
Obesity	13
Hypertension	8
Hyperlipidaemia	17

Patients were treated with systemic therapy, after failed treatment using topical or narrowband UVB phototherapy for psoriasis (Table 2). The mean time for the patient arriving into hospital and transitioning from topical/phototherapy to systemic therapy-for example with fumarate-was 2.3 years (range 1-12 years) and for methotrexate was 1.8 years. The transition to biologic therapy was 3.5 years (range 0-16 years) from arrival into the hospital system. 65% (74) of patients are on maintenance therapy with the original biologic they started with whereas 35% (40) of patients are transitioning through different biologics to attempt to develop disease control. The mean duration of therapy with etanercept was 3.7 years, 2.7 years for

adalimumab (both with ranges of 0.5-9 years) and 2.2 years for ustekinumab (range 1-6 years) (Table 3).

Table 2: Results obtained after treating with systemic therapy.

Previous systemic therapy	Number of patients
Narrow band UV-B	39
Cyclosporin	17
Methotrexate	79
Fumeric acid ester	23

Table 3: Results obtained after treating with bilogic therapy.

Therapy	Mean duration of therapy (years)	Range (years)
Methotrexate	1.8	0.3-7
Fumeric acid ester	2.3	0-12
Etanercept	3.7	0.5-9
Adalimumab	2.7	0.5-9
Ustekinumab	2.2	0.4-6

There were 41 patients on etanercept, 40 on adalimumab, 16 on ustekinumab, 14 on infliximab, 3 on golimumab. 106 systemic agents had been used prior to transition to biologic and 20 patients continued on combined systemic agent with their biologic-to achieve control or minimise antibody formation with infliximab.

In 2014, 64% (66,906) of 104,541 total referrals to dermatology in Ireland were made for the lesion assessment clinic and 61% (139,263) of 228,300 total referrals thus far in 2015. In contrast there were 36% referrals for patients with inflammatory skin disease in 2014 and 39% thus far in 2015.

Discussion

The quality of life for people with chronic skin diseases such as psoriasis, eczema, hidradenitis suppurativa and acne can be significantly impaired, and such impairment can be greater at times than for life threatening conditions such as cancer [7].

Psoriasis is a chronic autoimmune condition and it is estimated that 20%-30% of patients suffer from moderate to severe forms of psoriasis. The impact on quality of life in psoriasis patients, should not be under estimated and it is similar to conditions such as diabetes, coronary artery disease or asthma [8,9]. As a condition, psoriasis is associated with increased risk of developing microvascular and macrovascular events as well as increased risk of diabetes and metabolic syndrome [8-12].

In a recent prospective multicentre study in France, it was noted that there is a significant delay in the introduction of systemic treatment in moderate to severe psoriasis [9]. In our patient cohort, delayed access to the dermatology service contributed to the delay in patients starting systemic therapy or in severe psoriasis requiring biologic therapy as the mean time

period between GP referral and outpatient review was 11.6 months.

The significant delays may be explained in some part, due to the work pressure of the dermatology department and the limitations of this service under one dermatologist between 2001 to 2012. According to the Comhairle, report of the committee on dermatology services in 2003, the Irish Association of Dermatologists has recommended a target ratio of one dermatologist per 85,000 population [13]. With current trends and expanding Irish population, the ratio is currently in excess of this recommended ratio at 1/120,000.

Due to the limited health resources and delays, patient with uncontrolled psoriasis were more unstable by the time of review. In addition, significant proportion (55%) of these patients that were reviewed within 6 month of referral had severe psoriasis and eventually required biologic therapy reflecting inflammatory disease decompensation by the time of appointment.

Approximately 1 in 4 patient with psoriasis have moderate to severe disease and require second -line agents, which includes phototherapy (PUVA or UVB), and systemic therapies such as ciclosporin, fumeric acid ester or methotrexate [14]. The cost of biologic therapies such as etanercept, adalimumab, ustekinumab, infliximab can be estimated to range in excess of € 10,000 a year to € 42,800 a year [15].

The costs associated with delayed treatment of inflammatory conditions such as psoriasis can be measured in direct and indirect costs. The burden of these diseases can lead to work related disability costs, loss of productivity and more direct costs of prescriptions using topical, systemic or biologic therapies. As a result these delays in access can lead to further costs and disease burden.

Hospital management want dermatologists to mainly see new patients, prioritising those with skin cancer, but with little recognition of the cohorts of patients that need ongoing care for chronic inflammatory skin disease. Long waiting lists slow down the access of these patients into the hospital system leading to such patients developing more extensive and severe disease requiring powerful therapies.

According to recent central waiting list data in by December 2014, there are 357,793 patients on waiting list to see a Dermatologist, with total number of patients seen was 104,541, with 40,344 new referrals and 60,738 reviews. Similar trend in 2013, 103,339 were seen, with 42,601 new patients and 60,738 reviewed [13-15].

In first 6 months of 2015, nationally there were 228,300 more dermatology patients are on the waiting list. The same data in first 6 months of 2015, shows that 52,419 patients were seen. This data includes paediatric dermatology patients as well.

This study shows that patients with severe inflammatory skin disease face significant delays in accessing the hospital system.

This is partly due to inadequate infrastructure and staffing of Dermatology units. Although it is gratifying that two thirds of these patients have good control and can be maintained on their initial biologic a third of patients require different biologics to establish control. We need to make sure hospital and senior health service management understand the challenges posed by patients with severe inflammatory skin disease and the need for them to access dermatologic care in a timely manner and to provide the infrastructure to continue to manage this cohort of complex patients.

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