The Living with Asthma Study

Exploring the Quality of Life of Irish Adults with Asthma

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Foreword

With the fourth highest prevalence worldwide, asthma undoubtedly has a big impact on Irish society; but how does it affect Irish people's daily lives? In the Asthma Society we recognise that a better quality of life can be achieved by improving control of asthma symptoms. However, it is also the case that we need to understand the perceptions of people with asthma with regard to their quality of life before we can make progress on improving control. One cannot be achieved without the other and should not therefore be thought about in isolation.

This study is the first step in beginning an important new dialogue between the Asthma Society and people with asthma about quality of life. The study is extremely timely in that there is now an emphasis at national policy level to take a broader view in relation to the health and wellbeing of the population, with a stronger focus on staying well, rather than merely treating illness. The purpose of this Living with Asthma Study therefore is to give us a better understand of perceptions of health and wellbeing, the issues facing people with asthma, their views and their status, so that as a representative organisation we will be better informed to advocate on their behalf.

The study reveals some very concerning levels of dissatisfaction with the asthma health services. People are frustrated, they feel lost and abandoned by the system and describe their experiences of disjointed services and poor follow on care. The burden of the financial cost of asthma stands out in the report, with people describing how they skip medication and GP visits, travel abroad to buy cheaper medication and some telling us how costly it was making their homes asthma friendly – changing flooring, bedding, mattresses, etc.

The resilience and personal strength of people with asthma just jumps off the pages. They describe the relentless need to be vigilant and aware of your own body all the time and of the unpredictable nature of asthma with the constant fear of things getting worse. They are limiting their activity levels, giving up hobbies and withdrawing from social and family life because of their asthma. They are embarrassed about taking medication publically; they are being teased and seen as lazy, overweight and inactive. They feel that asthma has robbed them of their lives and feel very strongly that asthma is not taken seriously enough. These are very significant impacts on wellbeing and are without a doubt taking its toll. There is much learning for the Asthma Society and other stakeholders arising from this study. The urgency and importance of the implementation of the National Clinical Programme for Asthma is without question and we must continue to vigorously campaign for it. We need hard hitting public asthma awareness campaigns both for people with asthma and for people around them. It is also important that – asthma services (our own and the wider health services) develop further to take account of the impacts on the wellbeing of people with asthma and that we provide support and services which improve their wellbeing and their health. These must go hand in hand.

This Living in Ireland Study was kindly supported by Boehringer Ingelheim, whom I would like to thank. I would also like to express my sincere thanks on behalf of the Society to the participants of the Study who generously gave their time and provided us with a unique and honest insight into their lives and how asthma affects them.

Sharon Cosgrove

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Asthma Society of Ireland

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Section 1 Introduction

Ireland has the fourth highest incidence of asthma in the world (GINA 2004, 2012, Masoli *et al.* 2004). It is estimated that 14.7% of the population, or 470,000 Irish people have asthma, including 20% of Irish children, making it the most common chronic disease in childhood and the most common respiratory illness in Ireland (Asthma Society of Ireland 2014, Central Statistics Office 2008). Around 29% of people with asthma miss school or work because of it; adults are absent from work an average of 12 days and children are absent from school on average 10 days per year (Manning *et al.* 2007). There are more than 5,000 admissions per year to hospital for asthma treatment. The average cost of a hospital admission for asthma costs €2,737 (Health Service Executive 2009). The impact of asthma on people's lives has been well established. The recent REALISE survey found that a poor level of control persists among people with asthma, even though they rate themselves to be well controlled (Price *et al.* 2014). Symptoms and exacerbations of symptoms are frequent and this is not regarded by people as problematic, unlike their healthcare providers. This suggests that people are willing to put up with a level of symptoms which may influence their quality of life.

1.1Background

Quality of life has long been measured by the dimension of health; with health being considered in terms of physical health and wellbeing. According to the Department of Health, Irish people have had a history of recording high levels of satisfaction with their health in the EU-SILC surveys (Department of Health 2013a).This is based on self-assessment of health, with figures comparable to the European average among respondents even when considering chronic illness. The Survey of Lifestyle, Attitudes and Nutrition (Morgan *et al.* 2008) found that 58% of people considered themselves to be in good health, although 11% reported having a chronic illness. Asthma was among this number, with 6% of respondents reporting varying levels of quality of life. The detail specific to asthma is limited however, so we are unable to make inferences on those with asthma in comparison to the general public in this cohort. In the latest publication of the key health trends in Irish population 25.7% of men and 28.1% of women reported having a long-standing illness or health related problem (Department of Health 2013a). We do not know how many of these had asthma in particular, but it is interesting to note that just under half the number who reported a long standing illness reported that they are limited in their daily activities due to health problems. It could therefore be suggested that Irish people with long-term illness perceive themselves to have lower quality of life.

In light of the absence of specific illness data, and due to the prevalence of asthma among the Irish population it was deemed important to investigate quality of life issues further in order to ascertain if this is in fact the case. Reduced quality of life is frequently the cause of unscheduled attendance at a healthcare provider, and may not necessarily be due only to an increase in asthma symptoms (Eberhart et al. 2014). Wellbeing must be considered in addition to functional health status or control when considering quality of life issues for people who have asthma. Optimal control is linked

with health and wellbeing and we know that asthma symptoms are difficult to control. Adults with asthma and parents of children who have asthma are known to overestimate control and underestimate asthma symptoms resulting in poor control (Asthma Society of Ireland 2008, Rabe *et al.* 2004). This may be linked to quality of life issues, because of frequent hospitalisations, increase in asthma exacerbations, and an increase in risk taking behaviours such as smoking.

1.2 Quality of Life Research

There is a growing body of knowledge on quality of life research, and it is accepted that health is an important property of this multi-faceted concept (Hunter *et al.* 2013). There is much variation however in how health-related Quality of life is measured or how it is evaluated. This may be due in part to the unclear conceptual understanding of health and its impact on quality of life. There is a poor conceptual basis to many of the studies that have been undertaken because the concept of health is ill-defined. The WHO definition defines health as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'(WHO 1948). This definition has not altered in the years since it was agreed upon and is arguably inappropriate for those who have a chronic illness or disability. It is unattainable in its full sense if considered in these terms. The WHO advocate that when measuring health factors such as environmental, spiritual, psychological wellbeing, freedom or independence, physical capacity and social relationships should be considered (WHO 1993). There is wide variation however in how this has been measured mainly due to the differences in the understanding of the concept of health. Wellbeing is equally ill-defined with many studies combining the constructs of health and wellbeing, and measuring them as one concept. While health can be objectively measured, wellbeing is more subjective and relates to how people evaluate their feelings about their own lives (Tovar-Murray 2010).There is generally a balance between positive and negative feelings in wellbeing and this reflects the emotional and mental status of individuals. Personality can also affect how people with asthma think, feel and behave about symptom control and their quality of life (Axelsson *et al.* 2009).

Some argue that health is considered differently by health care professionals and those whose health they are measuring or evaluating (Eberhart *et al.* 2014, Makai *et al.* 2014). This is seen in the emphasis on symptom evaluation and compliance that is evident in the literature (Axelsson *et al.* 2014, Clayton 2014). Functional status or health status is often measured, even though this is illness orientated enquiry which may not necessarily be individuals' perspective on their quality of life (Drummond 2000). People with comorbidities are often not considered in this research also as they have complex care needs where there are often more than two chronic conditions to be considered (Mercer 2014). Measuring or evaluating health in terms of disease specific guidelines can be difficult for this group therefore, as they have to manage more than one condition in their lives. It is recognised that people with asthma are more likely to have multiple comorbidities when compared with the general population (Clayton 2014, Mercer 2014). They have greater risk of complications therefore, due to the combination of symptoms they experience, the drug regimens they are required to adhere to, and the level of treatment burden they experience, and this may be a factor affecting their overall quality of life.

1.3 Health and Wellbeing

There is a new direction in relation to the health of the nation, including those with chronic illness, where a cross-sector approach to tackling health has been proposed. The Healthy Ireland framework envisages a 'coming-together' of political, health service, voluntary sector, individual and community based organisations in maximising the health of the nation. The vision is for the population to be able to enjoy optimal physical and mental health and wellbeing, although these concepts are not well defined. Health and wellbeing are viewed as a resource, and are essential to allowing people to live their lives to the full of their own potential (Department of Health 2013b). Health is seen in terms of ill-health however, and the rise in negative trends of certain diseases and threats to public health. Strategies are proposed to tackle these issues in order to reverse the trends. The goal is to ensure that through our collective efforts, people can live healthier lives and have equal access to services.

The Healthy Ireland Framework includes objectives specifically to improve the health and wellbeing of people with chronic illness (Department of Health 2013b). Monitoring of the implementation of programmes and measurement of outcomes are encouraged, but this is not well defined as what is meant by health and wellbeing is unclear also. Health is defined as everyone '*…achieving his or her potential to complete physical, mental and social wellbeing'* and yet they add *'… is much more that the absence of disease or disability…'* (Department of Health 2013b, p9). This is aspirational indeed, and yet the use of 'complete' in terms of health makes this unattainable for those with chronic illness or physical disability. Wellbeing is considered as a dimension of health rather than a concept in its own right, but is acknowledged to effect quality of life. Healthy Ireland (2013) proposes a shift from viewing wellbeing in terms of what goes wrong to what goes well in people's lives. This is indeed a very different focus from the previous attention on quality of life in terms of the measurement of functional health.

The Asthma Society of Ireland can play a significant role in meeting the aims of Healthy Ireland in its advocacy role for people with asthma, and in particular by generating support for the introduction and national roll-out of the National Clinical Programme for Asthma (NCPA). The aim of the National Clinical Programme for Asthma is to achieve a 90% reduction in asthma mortality in ten years, to reduce GP out of hours visits by 5,000, and ED visits by 2,000; and reduce the occupancy of asthma bed days by 3,410 over three years. This will be achieved by implementing a National Model of Care, designed specifically with evidence based guidelines, care pathways, treatment protocols and care bundles for individuals with asthma (Asthma Society of Ireland 2014). The Asthma Society of Ireland recognises quality of life can be improved by improving control of asthma symptoms. However it is also the case that we must understand the perceptions of people with asthma with regard to their quality of life before we can make progress on improving control. One cannot be achieved without the other and should not therefore be though about in isolation. In light of this an investigation into the lives of Irish people with asthma was envisaged in order to develop a greater understanding of their perceptions of health and wellbeing.

1.4 Living with Asthma

The Asthma Society of Ireland is interested in understanding the quality of life issues for people who have asthma. We recognise that it is important to investigate this from the perspective of people with asthma and not just measure the negative impact of the condition on their lives. Control and adherence have been measured in many professional research studies and these issues have been established there. They are not the focus of this research therefore as professional interpretations of quality of life among people with chronic illness may not focus on positive attributes, or how people adapt to living with a chronic illness. There may also be a difference in focus in professional interpretations of the quality of life dimensions, which may not be appropriate for people with chronic conditions, such as asthma, as cure is not the goal of the service (Eberhart *et al.* 2014). In light of this we designed a research study to investigate the perception of the influences on quality of life, with particular focus on health and wellbeing, among Irish people with asthma.

Section 2 Methodology

A qualitative research design was used to explore the perceptions of people with asthma on their quality of life, and in particular in relation to the influences on their health and wellbeing. This allowed for meaningful investigation of the participants' perspectives, rather than approaching it from the position of one of the health disciplines or a professional standpoint. The qualitative design allowed the research team to gather rich, in-depth data from the participants' perspective (Moule & Goodman 2014).

2.1 Research Design

The research design utilised a qualitative enquiry involving participant focus groups. Qualitative interviews are useful in uncovering the persons' own views (Murphy *et al.* 1998, Polit & Beck 2012), so this was considered the most appropriate method for this study. The aim of this study is to investigate the quality of life of Irish adults who have asthma, with particular interest on the influences to their health and wellbeing. Understanding how they perceived the Asthma Society of Ireland and our representation for them nationally was also explored. The main objectives of the study were:

- to investigate the factors contributing to the health and wellbeing status of Irish adults who have asthma
- to explore participants' perceptions of health service provision
- to explore the level of satisfaction with the services provided to members by the Asthma Society of Ireland
- to investigate the issues members of the Asthma Society of Ireland wish to be pursued on their behalf.

2.2. Sampling

The study population was a convenience sample recruited from the Asthma Society of Ireland database of members, participants were invited to take part in focus groups in their local area. Recruitment was completed through direct member contact via the Society's social media networks, advertising on the society's homepage and through membership e-zine communication. Participants were also recruited from contacts to the nurse advice line. Participants were recruited from urban and rural areas throughout the country and grouped according to their geographical location. The initial advertisement for participants requested that potential participants contact the researcher with their geographical details and availability to take part in the research. Follow-up invitation e-mails were then sent to give further information on the study and explain the process to prospective participants. 38 participants volunteered to take part in the study from all over the country. Participants were offered a gratuity to cover their expenses in attending the focus groups.

2.3 Data Collection and Analysis

Data were collected over a six week period, in eight focus group interviews, 3 in Dublin and 5 in various locations across the country based on ease of access to the venue and participant availability. The focus groups lasted between 90-120 minutes. Focus groups consisted of 2-6 participants (n=31); there were some non-attendances at scheduled venues due to unforeseen factors in the groups of 4-6 which were originally devised. Participants were aged between 22-76 years, with 10 males and 21 females taking part. Venues were meeting rooms in locations that were accessible through public and private transport networks, had no-smoking rooms available and good disability access.

Data were collected in semi -structured interviews, which were audio recorded for analysis purposes. The flexible, semi-structured interview format allowed the researchers to explore the participants own perceptions rather than using leading questions based on professional preconceptions (LoBiondo-Wood & Haber 2006, Murphy *et al.* 1998). Field notes were also recorded during and after the focus group interviews. Two researchers conducted the focus groups for consistency; one researcher conducted the focus groups in Dublin and one researcher in the remainder of the country.

Inclusion criteria included adults (over 18 years) who have had the diagnosis of asthma for longer than 1 year, and who had a good level of verbal English language skill. Exclusion criteria included children less than 18 years of age, and adults who had poor levels of English language. Ethical approval was obtained from the local Research Ethics Board, and participants all gave written, informed consent at the beginning of the groups. They were assured of the confidentiality and anonymity of the data in all reporting and publications associated with the study.

Data were coded and anonymised from the recordings of the field notes and interviews, which were transcribed, and collated by one researcher for the purposes of data analysis. Data were interpreted by open coding, whereby the data were sorted and categorised into themes. Substantive codes were sorted to find relationships and look for variations. Naming categories became more selective and codes began to cluster into more refined categories as the analysis progressed. Findings are presented in descriptive accounts of themes that arose as a result of analysis.

2.4 Findings

The findings of this report are outlined in Section 3 of this report, in terms of the effects of asthma on quality of life, and participants' satisfaction with health service provision. The interaction with the Asthma Society of Ireland is also outlined in relation to participants' use of and their perceptions of service provided by the Society.

Section 3 Findings

3.1 Effects of Asthma on Quality of Life

Asthma was found to have a significant impact on the quality of life of participants due to the symptoms they experienced, the treatments they had to undertake, and the repercussions of uncontrollable events or exposure to triggers on their overall health and wellbeing. The unrelenting pressure of managing their asthma took a toll on many of the participants, who felt that their lifestyle had changed dramatically and they had lost some or all of their control over their health and wellbeing. They described how they could not participate in family outings and events, or how they could not participate in community activities so they felt outside their social network. Asthma was described as an 'unwelcome guest' in their lives, where they were forced to change their lives from what they knew before. Many said they used their asthma as an excuse when their morale dipped, as they had a fear of the consequences of trying new things or failing to reach their, or others' expectations. Anxiety was a major issue for all participants; the prime focus was to protect themselves by availing of any treatments or alternatives that could improve their quality of life. Dangers were perceived to be all around them and even within themselves, which were also out of their control.

Asthma was found to have an effect on both health and wellbeing, and while most participants considered themselves unhealthy because of their asthma they struggled most to maintain their sense of wellbeing. Health was viewed as something very physical, generally in terms of symptoms, issues regarding weight control and their level of fitness. Wellbeing was viewed as something more psychological and emotional, linked to a personal sense of authority and confidence. One was seen to influence the other, with particular focus on wellbeing as it dictated the degree to which participants engaged in healthy activities. Vigilance was important as having some level of control over their health was essential if they were to maintain their morale and sense of wellbeing. Managing anxiety was frequently described as essential in how participants maintained their motivation to be in control of their health and wellbeing. Issues concerning image, weight management, managing lifestyle, maintaining fitness, and managing triggers were important factors in how participants maintained their optimal level of health and wellbeing. Gaining stability and feeling optimistic were out of the reach of some participants and this negatively impacted on their health and wellbeing and their general quality of life.

3.1.1 Health

Health was seen to be influenced by physical factors and many of the participants considered themselves to be unhealthy. They considered themselves as unhealthy due to a combination of factors including weight issues and the physical level of symptoms. They felt out of control of their

own body and so restricted their activities in order to maximise what little control that they had. Every day was planned and activities were selected carefully following consideration of the consequences associated with them. There was a fear of raising their heart rate in case this had knock-on respiratory effects. Participants who considered themselves to be healthy discussed how they had developed as sense of intuition that they could read their bodies better than before. They felt that they knew their own bodies and were the expert on themselves as they had developed expertise on their own lives, and were happy with their level of physical symptoms. They wished that this would be acknowledged by healthcare providers, as one participant said

> '…it isn't always about the healthcare professionals knowing what is best for me. I know they mean well but sometimes I just wish they would (use of strong language) and actually listen to me for a change, I am the expert on my own body…I know my limits…' participant 11

Level of symptom experience and management were directly related to perceptions of health status for most participants. The physical toll of symptoms made participants feel that they were unhealthy as it restricted their choices in lifestyle activities. The majority of participants felt that they pushed themselves in order to maximise their daily lives, a determination not to be restricted by their asthma. Exercise however, was deemed impossible for some participants because of the associated increase in symptoms. Participants felt it was important to acknowledge their own limits and find their own rhythm. The most important thing was to keep trying and to never give up on themselves. There was a general acknowledgment that they were all different, no two people with asthma are the same.

> '…about three years ago I could walk 3 miles in 40 minutes, now I can do short walks only…physical activity cripples me…' participant 3

Weight was a major issue for both male and female participants, especially those on frequent or long-term steroid therapy. Those who had gained weight felt that their health was 'desperate' and they were 'not at all healthy'. In addition to their asthma symptoms the weight made them more self-conscious and less likely to take even light-moderate exercise even though they believed this would help them.

Poor physical health curtailed their family lives and they changed their lifestyle to accommodate this. Many resented the restrictions this placed on family life and the effect on the family in general. Others gave up hobbies as they were unable to sustain engagement without consequences. Sleep disturbances influenced general health as it affected energy and the ability to participate in daily activities as desired. For others poor physical health affected their home life, chores around the home were impossible and they described inventive methods of protecting themselves were discussed in relation to minimising the effects of dust, solvent, detergents etc. There was barter in many households where the chores were divided into those they could and could not do. This led to guilt and frustration on the participant's behalf.

> '…I just can't do the cleaning, my husband does it…I've tried to do the dusting but I need my inhaler and am up all night after…so I just don't do it…' Participant 17

Things that were out of the control of the participants affected physical health also. Air quality was discussed frequently in terms of the use of smoky fuels in urban and rural areas. Dust, traffic pollution and agricultural processes and production were also highlighted as problematic. The overwhelming common factor was that the participants felt they had no choice in how they lived their lives, it was not their choice rather asthma imposed restrictions on them. They felt that others are inconsiderate, especially when it came to smoking around them. Smoking was a trigger for everyone and the introduction of e-cigarettes was seen as a negative feature of Irish society. The surroundings such as work environments, retail outlets, entertainment zones and sporting venues are all viewed as hazardous places to frequent and they went well prepared if venturing out. They even felt that hospitals were dangerous places and welcomed the ban by the Health Service Executive on e-cigarettes recently. They always know where their inhaler is, even if they won't' use it in public. One participant said asthma was poorly understood. This is thought to be because it is taken for granted as it is so prevalent.

> '…people think it's a kid's disease…and I mean it's not sexy like cancer…like if nearly half a million people have it, it waters down how serious it really is. People think it's just like a cold'… Participant 21

There was a belief that the general public are unaware of how dangerous asthma is and how it affects people.

3.1.2 Wellbeing

Wellbeing was seen by participants as their emotional or mental state. Participants spoke about phases of wellness, periods where they felt better than others. They expected to feel worse at certain times of the year, or for phases of their lives because of their asthma. This was something they felt was out of their control and couldn't pinpoint why it may happen. There was the fear of deterioration in physical symptoms that they would not recover from and that this would impact on their health and wellbeing to a significant level. They felt that their attention to caring for their wellbeing was relentless, even exhausting at times, and that this was hidden from most people. They believe there was little understanding of what they did to maintain their wellbeing or the effects of this constant stress on their lives even though it took away so much of their energy. There was no escape from their asthma; many felt it impossible to accept their condition was permanent even though some participants had it for decades. Others felt constrained by their asthma as it was always at the forefront of their mind, they were constantly watching themselves. They did not act spontaneously and were overcautious as they feared having an exacerbation. Participants who reported having poor wellbeing resented how asthma had robbed them of their lives, how they could never put it to the back of their minds and for some how it affected their ability to stay in employment. For those who had better control of their symptoms it was evident that they had a determination that asthma would not define them. They accepted their asthma, even though this was uncomfortable for many, and were resigned to the fact they would have it for the remainder of their lives.

> 'I can't ignore it…I was very negative at the start and tried everything to avoid it but I just got worse so now I just have given in because this is it for me…' Participant 8

There was a great sense of fear among all participants that they would be overwhelmed by their symptoms and lose control of their own lives. Some felt they were in the dark, with no follow up so they did not know where to turn. This impacted greatly on their emotional wellbeing and as a result they isolated themselves from family events, work and social activities. Some felt that the only reason they did not totally give up was because of their dependents and they wanted to push themselves in order to meet their expectations of parenthood.

> '… yeah like I took the kids to the zoo and I knew I would be sick and I was. I suppose I have to take chances and make sacrifices to live…it is really cat…' participant 21

They felt that they would not internalise their feelings about asthma or how it affected their lives and it was hard to cope with. Most participants believed asthma had taken over their lives. They all just wanted to be normal, and believed that they would reach a plateau eventually, but when that would be was unclear. They feared that they would be viewed as lazy because of their asthma, whereas they felt it was their body letting them down.

> '…the stress is unavoidable and this can lead to an attack so I am always afraid, I'd give anything for that extra bit of air…my body just won't do it anymore..' Participant 1

Wellbeing was closely linked with security, and in particular a sense of financial security. There were major financial concerns related to treatment costs and how this impacted on life in general. Financial concerns were related to cost of consultations and medication charges, income and job security, and the adaptation of homes and changes in diet and lifestyle to accommodate asthma.

> '…I had to buy a hospital grade mattress with pillows and duvets, took up all the carpets, I don't take dairy anymore, it's really expensive but I have no choice…' Participant 23

The cost of attending medical consultations was highlighted as stressful as it was unpredictable and participants felt they had no choice other than attend. Many admitted that they left it longer than they knew they should to present for medical review because of the associated costs. Others had to give up work altogether due to the severity of their symptoms. For some participants the understanding of their employer was a welcome relief, as they frequently missed days at work due to appointments and unexpected consultations relating to their asthma. They did however worry about the implications for their social welfare payments when they were out of work for a period of time. Insurance premiums and mortgage applications were found to be affected due to their health status. Participants discussed how they had modified their homes, changed hobbies, moved jobs and even curtailed their size of their families because of the effect of asthma on their personal health and wellbeing.

> '..it's not a lifestyle choice…you have to do these things or you're just sick all the time…people do it even if they don't have the money, it's awful…' Participant 24

Learning to live with the condition and associated treatments was challenging for many of the participants. They resented how their choices in life had been restricted and how they constantly

had to compromise on what they wanted to do. They reported that they felt there was a huge difference between what they can do and what they wanted to do and this new normal was difficult for them to accept.

> '… I am broken hearted as this is it for me. I know I'll always have it, there is no cure…'
>
> Participant 31

Staying positive was essential in order to maintain wellbeing. Participants felt responsible for keeping themselves well physically and mentally. There was an envy of those who do not have asthma, who could do as they wish without having to think about possible repercussions to their health, or rely on medications. They were required to be constantly vigilant in managing triggers and staying ahead of their symptoms, although this had major emotional benefits for most participants. There was a fear of becoming dependent on medications however and the risk of pushing their limits too far was always in the back of their minds. It is a balancing act at times but one they felt they must try if they are to be less restricted by asthma.

> '…I am hopeful that I will feel better if I keep my eye on the ball...' Participant 29

3.1.3 Symptom Experience

There were long discussions and deliberations about symptoms and what constituted control for each of the participants. Many were baffled by their symptoms, and by how despite following the instructions of their doctor they did not feel any better. Symptoms were frequent and were overwhelming in terms of accommodating them into their daily lives. Some said they were lucky to be alive, because they knew so little about how to manage their condition and it was a miracle that they were not overwhelmed by their symptoms. Others perceived that they had good control and experienced very few symptoms. They faced fewer restrictions in their daily lives and could manage their asthma symptoms and exposure to triggers to a level of their own satisfaction. Four of the participants in the focus groups were receiving Omalizumab treatment with a specialist respiratory consultant. Those on Omalizumab felt that their lives had been transformed by the drug, despite the treatment burden associated with it. They felt that they had got their life back and they were no longer controlled by their asthma.

> '…I am a very positive person, nothing will stop me anymore…I feel so lucky in a way, Xolair has changed my life… I went to the Boston marathon and my son did it. Two years ago I wouldn't have been able to get on a plane so it has changed my life…' Participant 20

Symptoms were frequent for many but there was a consensus that they were uncomfortable with developing symptoms and taking medications in public. This is because it drew attention to them, made them different from those around them, which led to ridicule or teasing by others even their family and friends. They said they were embarrassed by their condition as it had changed them into a person they did not wish to be. They were unable to do the things they wanted and felt that their bodies were letting them down. They perceived common illnesses to affect them more than others

and there was a desire to get back to their previous normal. Some hid their symptoms and treatments from their closest family members, despite knowing that this was dangerous. Others were more proactive and involved their family in all aspects of their care, even educating them on what to do in the event of an exacerbation of symptoms. Many of the female participants discussed how they could not manage their symptoms due to fluctuations in hormonal levels associated with menstruation and during pregnancy. They found this especially difficult to manage but were reluctant to discuss it with their healthcare provider.

> '… I'm really fed up with it and when I get my period it's even worse…it's a double whammy for me…' Participant 17

It was acknowledged that the inhalers and other prescribed medications were essential in managing symptoms, but the number, frequency and type of medication had an impact on how participants viewed their health. If they had relatively few symptoms and could maintain their daily activities to their satisfaction on the prescribed treatments participants viewed themselves as healthy. The side effects of the medications however were seen to negatively impact on their overall health. Weight gain and lack of energy were particularly disheartening as it affected everyday activity levels and their ability to work and socialise as they wished. There was a dependency on the medications and security in having their inhalers close to hand at all times. This however caused great anxiety if they forgot a dose or could not remember where their inhaler was at a given point in time. The unpredictability of symptoms was a great cause of anxiety among participants. There was a general association between stress and oral steroid therapy as the participants did not like the effects the drugs had on them, from both a physiological and a psychological perspective. They avoided using them if at all possible and this is where the use of alternative therapies and treatments was relied upon in the first instance.

> '… I'm not happy taking steroids, alternative medicine is the way to go…I am much happier taking natural things…' Participant 18

Several participants had a low tolerance of symptoms before they took action. They self-medicated or presented themselves promptly for assistance. A large number of participants admitted however to waiting for much longer than they knew was safe before they presented to their doctor for treatment as they did not want to go on steroid therapy and were prepared to try anything else first. They claimed this was because they had no faith in the system. Managing symptoms was not without its consequences however, even for those who considered themselves to have good control. The long term effects of treatment were described as being another issues to come to terms with.

> '…the side-effects are awful; they wear you down over time…' Participant 8

Some had developed other conditions as a result of their asthma treatment, such as diabetes mellitus, and others had comorbidities which complicated their treatment. Participants wanted to be treated as a person, not just as a set of asthma symptoms. They felt that there was a one fits all system of management where they are not treated as an individual with specific goals and outcomes. They think this is because asthma is so common it has become less important. They feel that health professionals are judging them.

> '… I think they think I'm wasting their time, taking up a bed in hospital for someone else…they tell you you're fine and that they can only do so many tests…you don't know what step of the stairs you're on…' Participant 9

3.1.4 Use of Alternative or Complementary Therapies

Almost every participant had tried one or more alternative therapies to help them with their asthma symptoms. It was generally considered that trying an alternative therapy was worth the risk, and was preferable to going on alternative medication steroids. These therapies ranged from natural remedies, to physical or psychological therapies that were engaged on a sessional basis. The natural remedies or 'the cure' was typically available in their area, and participants had no knowledge of what was contained in it. These were found to have little or no effect in general. Some had attended healers, or given remedies like this to their children also, in the hope that it might have some effect on their asthma symptoms.

> '…I work with a girl who is into homeopathy and she gave me a remedy to try, put a drop into a glass of water and within a week she was better and has not been as bad since…' Participant 24

Cranio-sacral therapy, hypnotherapy, reiki, acupuncture and salt therapy were also discussed by several participants, with varying levels of satisfaction of their effects. Some found the therapy very beneficial whereas others had no effect at all and they disliked the environment so discontinued the practice. A small number of participants attended a chiropractor or physiotherapist to help with posture and breathing exercises. Many participants had tried yoga and found it useful in controlling their breathing and developing core strength. Others were trying mindfulness in an effort to manage their emotions, and their stress in particular in an effort to increase their sense of wellbeing.

> '…Mindfulness meditation is great, you breathe into your lungs as you are having the attack and it slows down your breathing…you are controlling yourself and letting it go…that is your wellbeing, being in control…' Participant 20

Others had tried Buteyko breathing but did not recommend it as having the benefits they had read about on the internet. Trying to manage symptoms with a primary focus on control of their respiratory rate and effort was acknowledged as a very risky practice and not one to be undertaken without the approval of their doctor. It was generally agreed that although the majority of participants were participating in some level of alternative therapy they would not discuss this with their doctor. Participants felt that their doctors would not approve and as long as they persisted with prescribed medication it did not need to be discussed. They felt it was worth it to try and feel better as the side effects of medications were awful and they would do this to avoid increasing or changing medications without the risk of the side effects.

> 'I go for salt therapy and it is brilliant…the first time I went I coughed and coughed but I felt great afterwards…I use the salt pipe every day, I bring it everywhere with me…' Participant 14

3.1.5 Support Systems

Support was viewed as an essential element in maintaining quality of life, and in particular a good state of wellbeing. Support came from a range of sources but the one that was particularly important was family. Having an understanding relationship with those around them on a daily basis was important to the participants.

> ' …my husband is brilliant, he'd even notice me being off colour and I'd be saying I'm grand but he'd tell me you're not, I know he recognises every bit of tightness…' Participant 13

Some participants felt very alone in managing their asthma even though their partner or spouse was aware of their condition. Others had family members who confused them constantly with suggestions on how they could manage their symptoms more successfully. This was an additional stress for them to cope with. There was a general sense that even though friends, colleagues or employers were aware of the diagnosis they did not fully understand or believe the extent to which the symptoms were debilitating to the participants.

> '…I'm very much on my own, very much…I have no support with it…even some people with mild asthma don't understand that when you're bad you can't do things…' Participant 4

Others had been frequently exposed to ridicule and teasing because of their symptoms or when taking medications when with friends so they avoided doing this in public as a result. This was believed to be as a result of the ignorance of asthma by the general public and added to the sense of isolation that the participants felt about caring for their health.

> '…I got slagged when I went away and I was being jeered for using the spacer and one of the comments was there is bingo on Tuesday, that is the slagging. It stuck… I'm like an old person with a bag full of medicine…' Participant 1

Participants reported that they had no support locally and that they hid their asthma from others because of this. They felt on their own and were annoyed by the actions of others who they felt were a danger to their health because of their behaviour. They felt that there was no general understanding about asthma and that some people just don't know what they were doing was harmful to them, whereas others were being deliberate and inconsiderate in their behaviour around them. Cigarette smoking, use of perfumes and aerosols, burning fossil fuels, gardening and other activities were detrimental to their health. They feel on their own and this was a scary thing but they tried to stay positive and resolved to just keep going and stop fighting it.

> '…my brother doesn't care at all, he'll light up and tell me to get a life…people have no consideration at all…' Participant 2

Fighting asthma was common with participants reporting that they tried various regimes of managing their asthma in order to feel better but eventually they figured out a routine that worked for them. There was a feeling that their bodies betrayed them and they had to get in tune with their

new normal, even though they resented this. Blaming asthma for their woes and all the stress in their lives was common even though they appreciated that this was not always necessarily the case. Getting in touch with their bodies and knowing their own limits was common. There was an acceptance that symptoms were inevitable and they just had to put up with them. This took a period of adaptation, and if there were any other comorbidity this was made more difficult. Most of the participants suffered from another illness, ranging from allergic rhinitis to type 1 diabetes. This complicated the management of their asthma as they had other factors to consider in addition to their asthma treatment. Having more than one physician added to this difficulty, as their focus was often different and this was confusing.

> '…different doctors approach things differently…some with honesty who will sit and explain to you what is happening…sometimes enough to help…' Participant 6

3.2 Satisfaction with Health Service Provision

The participants reported varying levels of satisfaction with their health service provision. In all focus groups there was a range in the severity of asthma symptoms and the levels of treatment provision; however this was not a major factor in how participants perceived their overall level of satisfaction with the service they received. If anything it strengthened the perception that there was great disparity between the services provided by the health service across all geographical areas. There was a general consensus that services here had improved significantly over the last number of years, however it remained unsatisfactory to the majority of participants. Waiting times, access to specialist services, variations in standards and approaches to care provision were all discussed as being significant issues in achieving better outcomes and subsequent improvements in the quality of life. Participants discussed the frustration they felt as they waited for results, updates and referrals and described it as exhausting.

> '...you're constantly chasing, chasing, chasing…' Participant 21

Some felt like giving up as they system was not meeting their expectations and they felt they were not getting better. They felt that they should feel better on the medications than they did, but that nobody was listening to them so they had no other options. Others felt that private patients got a much better service but had no real evidence to support this perception. However many participants felt nervous that they did not have private health cover as they perceived this to impact on their access to services. Those with private health insurance and called it their '*safety net'*. They felt disillusioned however with the system as they believed it was more concerned with generating profits than with them as an individual. One participant reported this as

> '…I told the (private) consultant the medicine wasn't working for me and she looked at me like I had two heads. I just wanted her to tell me what to do and instead she asked me what I wanted to do, maybe to come back to see her again in a few weeks, so I got fed up with them…it's not about me; it's all money, money, money…' Participant 1

Levels of satisfaction can be broken down into three broad service areas- access to services, monitoring and regular review, and partnerships with healthcare providers.

3.2.1 Access to services

Access to services was a major issue for all participants. There were varying levels of satisfaction with access to services based on geographical locations, and the range of services available to them. Those in rural areas tended to have local general practitioners (GP) as their main health service provider. A very small minority of these had access to a nurse specialist and those who did not have this access commented negatively on this. The majority of participants had changed healthcare providers on a frequent basis as they were dissatisfied with the service they received. Several participants travelled long distances from their home to access GP or specialist consultant services based on word of mouth, that Dr X had a particular interest in asthma, or had treated a relative or friend and was well rated by them. Several participants had moved GP on multiple occasions as they felt that they were not getting their symptoms under control and their doctor had run out of options for them. Others felt that their GP had just '…given up on me…' and they were disillusioned as they perceived the only service they received to be a prescription for medications (usually steroids) when they had exacerbations of their symptoms, with no follow-up care. Some participants felt that it is unfair to expect a general practitioner to have the in-depth knowledge they need to provide the type of care they require. They felt that their care suffered as a result of not having a specialist physician.

> '…I used to be steroid dependent and I spent a lot of time in the local hospital so I was giving up, they told me they were giving up and I was going to die…but then I went to Dr X and he said he'd heard the horror stories about me. He got me on a combination of drugs and I was running out the door. Having a specialist is great; it makes a big difference…' Participant 20

Access to emergency treatment in emergency departments was also strongly criticised. Waiting times for ambulances in both rural and urban areas were commented on, with several participants reporting they were reluctant to call for an ambulance and preferred to get to an emergency on-call GP service by any other means possible in order to gain quick access to treatment. One lady spoke about a 40 minute wait, during which time she was on continuous nebulised bronchodilators. Her symptoms improved slightly and when the ambulance eventually arrived she was chastised by the crew for calling them out. When admitted to emergency departments there was also a poor level of service provision according to participants. They remained on trollies for long periods of time, had prescriptions provided when they were well enough for discharge and were sent home without any follow-up referral. This occurs even when they have frequent readmissions to the same unit. There is a delay in notifying their general practitioner of the event which compounds the frustration with the service.

> '…they give you something in A+E and tell you you're fine and I say you should have seen me at 3am… I mean you wait to be seen and then they ask you what the plan is, your meds aren't working and you're getting worse and they look at you and tell you to go home, you

> don't need to see the GP. Then I go to my GP and she doubles up (on medications) what they said…she seems to know what she's doing…' Participant 3

Several participants had learned the routine of the healthcare system in order to bypass emergency departments altogether and instead present themselves to outpatient clinics on the days that they knew they were held. This was in order for them to see a respiratory physician or gain access to medical assessment units where they had greater confidence in service. Learning the system helped them to navigate access to their trusted physician.

> '…the hospital has great people but to get in to see your consultant is a nightmare. I have just landed in on the day of a clinic, it's a Wednesday, so don't get sick outside of that…' Participant 21

Access to nurse specialists was a major source of discontent, especially for those who were managed by a GP who was not supportive in referring them on. Requiring a consultant appointment prior to gaining this access to the nurse was seen as a major negative as it slowed down the process or stopped it altogether. Nurse specialists had a very positive influence on all the participants who had accessed their service and were highly regarded as being practical and easy to talk to.

> '…I asked for a local referral so I met the nurse who was better than all of them, she was brilliant. She rang me regularly to check and I was great. She gave me a spacer and a peak flow and I was super when I had access to her…' Participant 1

Participants expressed satisfaction with their service when they met a physician who had an interest in them and their asthma, or if they had access to ancillary healthcare professionals such as asthma nurse specialties, or received more complex treatments. There was overwhelming agreement that in order to have faith in the service, trust must be established with their healthcare provider, whoever or wherever they may be.

> '…I moved to here and the doctor took interest in me, he opens early and has a real interest in asthma. He has a nurse every two weeks…' Participant 5

Medication use and availability was seen to affect participants' satisfaction with services also. The cost of medications was a huge issue for participants voicing much dissatisfaction with the dispensing charges and practices in pharmacies across the country. Some had no difficulty having multiple medications dispensed whereas others found they were only getting one month's supply at a time, even though on occasion there were insufficient doses in the one month pack for the calendar days.

> '…every month I have to get inhalers but the worst thing is you have 2 or 3 of them on your prescription but they'll only give you one…' Participant 27

Many participants travelled out of the jurisdiction to have prescriptions dispensed as a result of the costs associated with medications. Others had relatives in the UK who posted medications to them, while a few participants admitted to buying their medications in large quantities when away on holidays. One had considered buying the on-line from an American website but decided against it due to the recent media attention on counterfeit or substandard on-line medication supplies.

Participants also admitted to skipping doses as they could not afford to renew prescriptions, which was a risky strategy but one which they felt they had no other choice in. Others stopped taking their preventers for a while as they could not afford them. They waited until payday to renew their prescription even though there might be days in between the last dose and when they filled their prescription.

> '…you pay for it, it costs me so much…I spend €144 per month which I think is unfair for an ongoing illness…the recession has hit me I have gone without my inhalers as I can't afford them at times…' Participant 19

The recession had had a massive impact on their financial stability and those who classed themselves in the middle income bracket, without a medical card felt they were getting hit the hardest. There was no help for them. There was an overwhelming call for medical cards to be made available to people with asthma as a result of the costs incurred in treatment. There was bewilderment that even though Asthma is recognised as a chronic illness they were not entitled to a long-term illness card or a medical card. Several participants had discretionary medical cards and were experiencing huge anxiety given the review that was underway at that time, as there was the potential that these would be removed from them. Others felt that a medication card rather than doctors visit card should be the standard as it is the cost of medications that place most pressure on them.

3.2.2 Monitoring and Review

The general consensus is that there is no consistency in service provision and there is no standard approach by health care providers in assessing people as individuals, involving them in the planning of their own care, or in follow-up care for their asthma. The majority of participants felt that they were just started on inhalers and that's where the discussion with their health provider stopped. They never had their inhaler technique checked, the majority did not have and had never heard of a personal asthma plan, and reported that they just got steroids during an exacerbation and there were no options discussed or offered to them. The services did not meet their needs and the healthcare professionals they dealt with were too busy to discuss their asthma in any depth with them. Many felt that they were 'lucky' to have access to the services as it was down to the goodwill of others, or they knew someone who could 'get them in' quickly if they needed assistance. There was general agreement that the effect of asthma on their lives was underestimated by those they encountered in the service.

> '…I would like to have a conversation with my doctor where he would re-evaluate my asthma. Despite him being my doctor for ten years he never asks me how my asthma is, he is not interested…' Participant 17

There were several flaws in the Irish system, as perceived by the participants. An inequity in service provision was felt by many participants as they did not have private health insurance so were on long waiting lists to be reviewed and had no direct access to a specialist respiratory consultant.

Participants felt there was no follow-up on their presentation to emergency departments and that it was a stop-gap facility. The provision of primary care was also heavily criticised by many. In seeking an improvement in services many participants compared our national service to those in other jurisdictions. The countries most commonly used to compare services for people with asthma were the United Kingdom and Spain. A number of participants had lived in these countries and had returned to Ireland. They discussed the primary health networks and access to a range of healthcare professionals in the community there. They discussed the monitoring and ongoing review and support they received there, in addition to the costs associated with these services and medications in particular. Other participants had relatives or friends living in other countries and discussed similar issues.

> '…I had it in England, saw a consultant once every 3 years, I didn't need my reliever at all…I had access to my GP and an asthma nurse whenever I needed to and it really made a difference…' Participant 2

3.2.3 Partnership Approach

How participants interact with healthcare professionals is broadly seen to dictate their level of satisfaction with the level of service they receive. Several participants had developed a partnership relationship with their healthcare provider and were very satisfied with the service they received. This was because they felt they had an open, two-way communication with their HCP whom they felt took a genuine interest in them. They felt their HCP was providing them with information and support that was having a positive impact on their asthma which in turn impacted on their general health and wellbeing. They felt positive and that they had their asthma under control and knew what to do in order to maintain this. Those who attended specialist consultants were generally more satisfied with the service they received, however it should be noted that the majority of these participants were on Omalizumab so had regular appointments and access to clinical nurse specialists on a one-to-one basis.

> '… I travel up to get it every few weeks, it's worth it… and I get checked by the nurse when I'm there and after the injection. They all know me and I mean so we get chatting. It has changed my life…' Participant 16

This security was not evident in all participants however. Those who were dissatisfied with their partnership relationship felt that they got inadequate information or advice. They felt that their healthcare provider did not believe them and was either uniformed themselves or reluctant to discuss their asthma with them in any great depth. As a result there was little advice or information given to them, and they did not know where to access information for themselves. They sought information from alternative health practitioners, groups on the internet and others with asthma they met in an effort to reduce the risk to themselves. They struggled with independent information seeking as they were unsure how to recognise the credible sources they should access and were confused by the volume of material available. Others discussed how their health provider spoke to

them using jargon that they could not understand and this made them feel powerless as they could not understand what was being said to them.

> '…my doctor is only so-so…it is hard to get a good doctor…I mean I don't know how people are meant to know what interactions to have with him...' Participant 5

Only a minority of the participants had a personal asthma plan or knew about the 5 step rule, even though they had all experienced an exacerbation of symptoms and were treated at that time. Others claim that they were instructed incorrectly on how to use their inhalers, with several not receiving any instruction at all from either the prescriber or the pharmacist who dispensed the medication to them. They spoke about learning to filter the good from the bad advice over time, but reported that

> '… you figure it out yourself eventually but it is dangerous until you work it out…'
>
> Participant 31

Several participants felt that health service providers had given up on them entirely and had little interest in their health. There was a general lack of awareness of treatment options and treatment guidelines among all participants. They had their own experience to refer to and very few had met others with asthma and discussed their experience with them.

3.3 Interaction with the Asthma Society of Ireland

For some participants, participating in the research was the first direct, personal interaction they had with members of the Asthma Society of Ireland (ASI). The majority had used a number of the services available to them as members, but there was frequent surprise at the range of services they had not been aware of. Many participants had attended the review clinics or pharmacy nurse-led clinics and they reviewed them positively. The free membership was warmly welcomed and the advice line was frequently described as wonderful. Several participants had used it and a few called it their lifeline. They wished it was available for longer each day as they found it difficult to coordinate their work with the times the nurse was available.

> '…she's my lifeline but sometimes I wish she was there all day as I can't get time off to ring in the mornings…' Participant 3

Participants rated the website favourably and commented on the quality of information available to them. A minority of participants had used the Asthma Coach App and liked it, although they preferred the Met Eireann app as they believed was quicker to access the pollen feed there. Some found it difficult to read the PDFs on their smart phones and so considered the booklets more preferable. They felt that the ASI were investing in them, especially this research as it was the first time they have spoken so openly about their asthma. They didn't feel they could say these things to their doctors as it would negatively impact on their treatment, but as ASI was independent they could give an honest account of their opinion.

> '…yes it definitely helps to have someone to talk to, my doctor wouldn't listen like that…the power of the Society is a big help…' Participant 18

They want the ASI to keep campaigning for the medical card, cheaper medications and for the improvement in air quality. There was little or no knowledge on the National Clinical Programme for Asthma but when it was outlined to them participants thought it was a great idea. They would like more links to information that could help them in their day to day lives. They love the newsletters and the e-zines, but found the fundraising phone calls to be a little intrusive, as were the charity street collectors. Many wondered if these were authorised sellers and where the money went to in light of the recent scandals in the charity sector.

> '…keep going with the medical card campaign, I'm delighted to be part of this and am dying to hear what will happen with it…I love the fact you contact me regularly with the updates, I learn so much from the stories..' Participant 20

An awareness of how to help in the event of an exacerbation is essential and they called for a campaign to promote this similar to the CPR campaign. Role models such as sport stars or entertainment were good at getting the message across, and participants believed this might stop the negative behaviour and attitude of others and how it affected them. Participants suggested that if their family and friends learned more about the condition they might not be so judgmental. Others suggested that a series of local campaigns would raise awareness of the dangers of smoky coal in their towns as there was little understanding of the effect it has on them. They wouldn't feel so embarrassed by their condition if people understood it more.

> '…It would help too as I'm not sure I could manage in an attack, I wouldn't know what to do and people probably assume that I do…' Participant 9

Participants were very happy that this research was not only for people with asthma who lived in or around Dublin. There is a general feeling that all the services and supports are in Dublin and the rest of the country is left out. They would like access to ASI drop in health information stands in shopping centres, at big social events such as hurling and football matches, Bloom, the Ploughing match and other events to raise the general public awareness of asthma but also as a resource for them. There was a consensus that the ASI should be a source of information to the general public to develop an appreciation for what it is like to have asthma. Hard hitting campaigns were requested, as they felt that people don't take asthma seriously and they suffer as a result.

> '…they need to see someone having an attack and then they'll know, otherwise you have to manage your symptoms as best you can cause no-one really gets it…' Participant 27

Participants felt that they had gained from their participation in the focus groups, in addition to contributing to the research. Many were surprised by the frank and open discussion they experienced. They were interested in meeting others with asthma either somewhere that was part of their treatment where they can get advice and information, or in local groups facilitated by ASI. They wanted to learn more particularly about alternative therapies or other treatments that would help them cope with the stress associated with having the condition.

3.4 Conclusion

Participants reported that asthma had an impact on their quality of life, and generally considered themselves to be unhealthy, irrespective of their perceived level of control. There were several factors influencing their quality of life and in particular their health and wellbeing, including symptom experience, the use of complementary or alternative therapies and the availability of support. They were critical overall of the health service and in particular access to specialist health care professionals. They had a good level of satisfaction in relation to their association with the Asthma Society of Ireland but made several suggestions on how this could be improved. The findings of the research will be discussed in the context of the study aims and objectives in section 4.

Section 4 Discussion

The findings of this study are a welcome addition to what we know about asthma control and management. They give an insight into people's own perceptions of the influences on their quality of life, and in particular what effects their health and wellbeing. We know that adults with chronic illness are more likely to report lower levels of quality of life (Strine *et al.* 2008). Quality of life is not merely a result of health status; rather it is a measure of how well individuals rate their level of ability to participate in relationships, activities or experiences as determined by their own values (Drummond 2000). Psychological as well as physiological factors are well known to affect perceptions of quality of life among people with chronic illness (Malec 2002). Coping skills have been shown to have a powerful effect on how people with chronic illness perceive their quality of life (Wallis *et al.* 2006).

4.1 Quality of life

Asthma was found to have an effect on the perceptions of quality of life of all the participants. There were varying degrees of symptom severity but this was not seen to dictate the overall level of satisfaction with quality of life. The majority of participants considered themselves to be in poor health because of the chronic nature of their diagnosis. Functional health status was important, but was not the primary focus when rating their overall state of health and wellbeing. This is similar to other findings where asthma was found to have a greater effect on mental and emotional health than physical health (Knoeller *et al.* 2013). They also found that there was a weak relationship between asthma severity and health related quality of life.

The findings of this study suggest that health and wellbeing are intrinsically linked, but may not necessarily always coexist in equal measure. Symptom severity, weight issues and levels of fitness are all seen to affect health, but these are dictated more by people's emotional and mental wellbeing than by their asthma management regimen. There was an acceptance that symptoms would exist and that medications were essential in the management of their asthma, but there was a general malaise regarding the success of medicinal based interventions in isolation. They were viewed as only one part of the jigsaw in maintaining an acceptable quality of life. Personal resilience and determination to fight the control asthma had over their lives was evident, even in people who had asthma for decades. There was a determination that they would not let asthma stop them from being in control of their lives. Those who did not feel this sense of control over their lives felt that the system was not supporting them as well as it should, or there were external factors influencing their lives that they could not control. This included social, occupational, environmental and financial influences.

Mental health and emotional wellbeing were found to be powerful indicators of how participants perceived their quality of life. Stress and anxiety in particular were found to have a significant impact on how health was viewed overall. There was frustration and disappointment among participants

who felt that their bodies were letting them down and as a result they were unable to do what they wanted to do most of the time. Although they tried to push themselves there was a constant threat of unpredictable exacerbation of symptoms. Disturbances in sleep pattern were reported as having a detrimental effect on both mental health and emotional wellbeing. Participants felt they were unable to cope with stress or anxiety if they had poor sleep pattern. Sleep quality has been shown to have an effect on health related quality of life and this is linked to symptom control (Becker *et al.* 2014).

Lower satisfaction with body image and frustration at restrictions to levels of activity due to an increase in weight were distressing to both male and female participants. Lower levels of life satisfaction have been linked with levels of obesity, and in particular when this co-exists with the presence of a chronic illness (Strine *et al.* 2008). It is well known that obesity can affect symptom control and result in more frequent attendances to health care professionals (Scott *et al.* 2012). This is linked to lower levels of reported quality of life. A different approach to managing weight gain, especially those on frequent or long-term steroid therapy might be useful in addressing this issue and increasing a positive sense of health and wellbeing. Setting realistic targets and minimising the negative effects of treatment by advising people on diet and exercise could maintain people's efforts to control their weight. This would have consequences on symptom control also. Resilience was found to be important to people with chronic illness when considering their own health (Simon *et al.* 2005).

Control of symptoms was not the emphasis of how quality of life was perceived by the participants in this study however. Only a minority of participants had a personal asthma plan, with most never having heard of them. Participants were prepared to tolerate a level of symptoms if they were able to participate in family activities, maintain their employment and recreational activities and avoid changing their medication regimes. This would appear to support the claim therefore that measuring quality of life in functional status or levels of control and compliance, although useful, may not capture individuals' true perceptions of their own lives (Drummond 2000). Physical health, mental and emotional wellbeing, and social influences were found to have the greatest impact on how participants evaluated their quality of life.

The use of alternative therapies and treatment was widespread, even though it was agreed that this was without the consent of their physician in most cases. The variety of therapies that were used was based on a perception of either benefit or enjoyment of the treatment. There was a considerable level of expenditure on these therapies, even though the costs of conventional treatments were highly criticised. Although there is some evidence to support the use of alternative therapies, such as yoga, to help improve control and consequently quality of life (Bidwell *et al.* 2012, Hunter *et al.* 2013) there are no particular alternative therapy or treatments recommended for all people with asthma.

Support systems were seen as essential in how participants maintained their quality of life. The primary support came from within their families, although this was also seen to be a negative influence when they interfered too much in management issues. Like adolescents, many participants reported that they were exposed to teasing and some ridicule when taking their medications, even

by friends and family that were aware of their symptoms. This had a negative effect on their symptom management in social situations and affected their self-esteem in general.

4.2 Satisfaction with Health Service Provision

In this study, having confidence in health services was found to be related to ease of access to a physician, access to other healthcare professionals, and having a GP/consultant who was interested in asthma. Participants moved frequently until they found a doctor they had confidence in, and this influenced their quality of life. Other studies have also reported a higher level of health related quality of life in those who are treated locally and felt they had their needs met (Hoffmann et al. 2008). Compliance levels rose among this group also as their perception of barriers to care were reduced by having access to local services. In this study participants who reported having a poor local service also had higher levels of symptom experience and attended emergency departments frequently for treatment of exacerbations. Health-related quality of life in people with asthma has been found to be a predictor of higher attendances at emergency departments (Magid *et al.* 2004).

Health and wellbeing are representative of both physical functioning and emotional or psychological issues that impact on their subjective wellbeing (Makai et al. 2014). Participants perceived that this was not considered as important as the control of asthma symptoms by health professionals. It is suggested therefore that perhaps more attention to improving the wellbeing of people with asthma is required in order to increase the satisfaction with service provision. There is an obligation on health care professionals to be up to date and think differently from just managing symptoms if people are to adhere to medication regimens and improve their control (Clayton 2014).

The cost of accessing health service providers and prescribed medications and appliances was heavily criticised by participants in this study. The majority of participants felt that they were not getting value for money and that the costs here were much higher, for a lower level of service, than in other jurisdictions. The cost of medications in particular caused much anxiety and was seen to influence emotional health and subsequently compliance with treatment. Many participants felt this was out of their control, and their difficulties were exacerbated by dispensing practices in their local pharmacy. Attending medical appointments and paying for medications were the major income related stress in their lives as the majority of participants did not have access to the medical card scheme and were on multiple medications.

Participants in the study called for a more inclusive approach to managing their asthma, calling for a partnership with their healthcare provider. Being active participants in planning one's own care has been shown to have a positive effect on people's perceptions of their quality of life(Malec 2002). Patient centred approach is proposed especially for those people who have comorbidities (Jeon et al. 2010). Participants called for greater openness and exchange of information in their interactions with healthcare professionals. Achieving a balance in life is seen to be more possible when people feel included in the planning of their own care (Jeon *et al.* 2010). A partnership approach to the provision of healthcare, especially for those with illnesses such as asthma was found to have a positive impact on overall health and wellbeing as care is patient-centred.

There was much debate over the advantages and disadvantage so having private health care and if this affected the quality of service participants received. Access to private health insurance has been shown previously to affect perceptions of quality of life the older generation who have chronic illness (Jeon *et al.* 2012). They found fear among older adults who had co-morbidities that without private health insurance they would suffer a reduction in access to health services, even though they had no proof this was the case. Participants felt that their health insurance guaranteed them quick access and treatment, which they would not receive in the pubic system (Jeon *et al.* 2012). Similar fears were voiced in this study and those who had insurance reported that it would be the last thing they would give up in terms' of financial savings. They felt that it ensured them access to their consultant and asthma nurse, something highly rated in terms of maintaining their quality of life.

4.3 Relevance to the Asthma Society of Ireland

This study investigated the quality of life of adults with asthma in relation to their health and wellbeing. It is timely in that the Asthma Society of Ireland is currently campaigning to have the National Clinical Programme for Asthma implemented. The findings provide robust evidence of the perceptions of people from across the county who have asthma in relation to how they perceive their quality of life. This strengthens the call for implementation of the NAP by Asthma Society in representing the views and status of their members. A standardised national approach to managing asthma, in terms of access to services and information, would undoubtable address many of the criticisms of the service raised in this study. Providing a person-centred healthcare system would ensure it is orientated to address issues of health and wellbeing, as they have been shown to be mutually dependent here in terms of quality of life issues. Reframing the primary focus of asthma management from compliance and adherence to one which is centred on individualised care, may facilitate a more open discussion of quality of life issues between healthcare professional and patient and could increase the level of symptom control.

4.3 Limitations and Recommendations

A strength of this study is that is afforded participants an opportunity to express what they thought about the factors which influenced their quality of life. The focus groups were open and conversational and interviews proceeded without the preconceptions of the facilitators influencing the direction of conversation. This did result however in several topic areas not being discussed, such as sexuality for example. This may have been because of the age or gender-mix within the groups, but because it was not raised as an issue the topic was not explored in any great depth. It is recognised that this is a limitation to this study; however this does not reduce the power of the findings overall. It is recommended that further research be conducted to explore the meaning of health and wellbeing in all its contexts to ensure that a deeper understanding is achieved. This could include all the properties of health and wellbeing that are seen to influence quality of life from the

perspective of people with asthma, rather than the illness-focus approach that has been used previously to explore the concept.

The findings in this report will be used to support the development of new strategy initiatives by the Asthma Society of Ireland. Acknowledging the contributions of the participants in this study will guide new policy initiatives in the areas of addressing stigma, access to services and lifestyle issues. It is a new baseline for understanding the perceptions of the members of the society with regard to living with asthma and can strengthen the call for the implementation of the National Clinical Programme for Asthma.

4.5 Conclusion

Quality of life is influenced by many factors, but in particular health and wellbeing. This study provides an in-depth insight into how people with asthma perceive their quality of life in Ireland today. It could facilitate a change in service provision by health professionals in addressing the needs of the population that they serve in their clinical setting. Findings suggest that functional or physical status or measurement of symptom control should not be considered as the only measure in how people with asthma rate their quality of life. Health and wellbeing should be addressed as separate, yet co-existing requirements in optimising the quality of life of people with asthma.

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