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It is with our great pleasure to present you this issue of the Children’s Research Digest, focusing on “Improving Child Health Through Research”. Children make up one-third of our global population and represent the future. According to the World Health Organization’s definition (WHO, 2000) “child health is a state of physical, mental, intellectual, social and emotional well-being and not merely the absence of disease or infirmity. Healthy children live in families, environments, and communities that provide them with the opportunity to reach their fullest developmental potential”. Global child health has improved significantly in the past decade due to evidence based policy and practice that has quantified health problems and identified strategies such as diarrhoea management, breastfeeding promotion, mother-to-child transmitted diseases (e.g. HIV), amongst others. There has been remarkable progress in reducing infant mortality and maternal death through expanding the research and policy based reach of programs (WHO, 2016). Deaths among children under-5 dropped from nearly 12 million in 1990, to about 5.9 million in 2015.

New figures from Eurostat, the EU’s statistical agency, shows that Ireland has the highest birth rate for 2016 (11.0 per 1000 live births), which means 63.9 births per 1000 residents. The infant mortality rate (IMR) for Ireland (2012) is at 3.5 per 1000 live births, 33% lower than the 2002 IMR rate and lower than the European average of 3.9 per 1000 live births (McGarry, C. et al. 2013). Ireland registered the lowest death rate at 6.4 deaths per 1000 residents. In the context of births relative to deaths, Ireland shows the greatest natural increase of population (Eurostat, 2017).

Less impressive are other health statistics from Ireland. Recently reported exclusive breastfeeding rates in Ireland on discharge from maternity hospital is 46.3% (HSE, 2016), yet only 15% are exclusively breastfed for their first six months of life, a very low rate compared to the global average of 38%. The promotion, support, and protection of breastfeeding are a top priority set by the Department of Health (2018) in Ireland to ensure optimum growth and development for children. In 2016, the HSE published a Breastfeeding Action Plan 2016 - 2021 which sets out the priority areas to be addressed over the next five years to improve breastfeeding support, to enable more mothers in Ireland to breastfeed and to improve health outcomes for mothers and children in Ireland. It is interesting to note then that the budget set aside nationally for the promotion of breastfeeding was pulled entirely earlier this year. This is alarming as research evidence suggests that breastfeeding is not only a protective factor against childhood obesity but also plays a pivotal role in the prevention of chronic diseases including diabetes (Victoria, 2016; Yan et al. 2014).

Worrying then is it that a Childhood Obesity Surveillance Initiative (COSI) report (2017) highlights that at least one in five children are overweight or obese, which ranks Ireland in fifth place among 27 EU countries. Childhood obesity is a multifaceted issue in the population health and well-being, and in Ireland; this issue needs to be addressed as a research and implementation priority to tackle the causes and adopt preventive measures. Otherwise, this will have far-reaching consequences for the population health and put more financial burden and resource constraints on our health care system.

Another important issues is that of children living with life-limiting conditions such as rare diseases and genetic disorders. The prevalence of children and young people with life-limiting conditions have been increasing dramatically (Fraser et al. 2011, 2012, 2015; Ling et al. 2015) due to improvements in technology and better clinical management of certain conditions. Early individual diagnosis for life limiting conditions is spread out across various rare diseases, collectively children requiring complex care for these conditions are of a larger proportion than any other chronic conditions (Royal College of Paediatrics and Child Health, 2014). In Ireland, there are approximately 3,840 children living with a life-limiting condition (Ling et al. 2015) and in the region of 490 deaths per year (DOHC, 2010). The former Department of Health and Children (DOHC, 2010) recommended multi-disciplinary research initiatives to develop an evidence-based contribution to children’s palliative care in Ireland.

Strengthening national research capacities to respond to local health needs is fundamental for the implementation and sustainability of research findings at population level. In response to Ireland’s changing health and well-being needs, the government has introduced many initiatives to tackle Ireland’s current needs to promote child health. Healthy Ireland’s framework envisions “a Healthy Ireland; where everyone can enjoy physical and mental health and well-being to their full potential; where well-being is valued and supported at every level of society and is everyone’s responsibility” (HSE, 2017). The National Healthy Childhood Programme is another initiative and has a key role in supporting families so that young children are enabled to realise their full potential and grow into healthy adults. Recently, the Irish National Clinical Programme for Paediatric and Neonatology have developed the Paediatric Early Warning System (PEWS) which provides a framework for care and empowers clinicians to act on behalf of any child with signs of deterioration or about whom they have a clinical concern (RGN, 2017). These programmes are some recent key priorities set by the government agencies and funding bodies.

At international level, Every Woman Every Child is a multi-stakeholder movement enlisted into action under the Global Strategy for Women’s, Children’s and Adolescent’s Health (2016-2030), by the UN Secretary-General in September 2015. It calls on all partners to unite and take coordinated action to achieve real progress for every woman, child and adolescent everywhere. To achieve optimum health for children and their families, government agencies and policy makers need to ensure that children are offered a better place for their healthy growth and development, reducing child morbidity and mortality, creating awareness of children’s protection and safety as well as supporting children and their families’ psychosocial needs. To maximise efficiency and effectiveness of research into child health and development, it is essential to draw research priorities based on population needs. This should be based on evidence and ethical considerations to offer collaborations between national and international agencies to improve health and well-being for children and their families. Government policies need to recognise the need for early intervention and prevention programmes in contributing to better population health and in tackling inequalities in health (Department of Health, 2013; DHSSPS, 2010). Mc Avoy et al. 2013, reported that there is a need for “Integrated child development and health services in the community and linked to the family home present opportunities for multidisciplinary working and synergies in the delivery of child services” and continues “Further reflection is required in terms of supporting appropriate prevention and early intervention approaches in the school setting”, (pp.3).

Apart from early intervention, prevention and nutrition, it is paramount to understand the concept of genetics and genomics, epidemiology, diseases management, outcome measurements and impact of illness on children and their families. “The family is an integral part of how children and young people experience and express their illness” (Ingrid, et al. 2014, pp.9). Imagine if you are a parent of a child with a serious-acute chronic illness and how stressful it will be for you to undergo the complicated process of caring for your sick child on a day-to-day basis. This editorial is also a call for more programmes of research which will examine the impact of illness on families’ day-to-day lives, and their physical, mental and psychological health, so that research evidence can support implementation of improvement plans including therapeutic conversations between families and professionals and how to disclose genetic diagnosis to a family.

As health care professionals working with children, we should strive to support their improvement through more research and surveillance, clinical and service standards, quality improvement, clinical audit and policy and practice development.
Research has resulted in substantial progress in child health and quality of life over the number of years, however, many problems remain to be tackled to improve child health globally. The concept of involving children in research has gained credibility recently (Kellet, M. 2010). As co-investigators they attempt to demonstrate a unique “insider” perspective on their status in the society as children or young people. This participatory approach in health care research will offer an accurate picture of children’s role as consumers in health care systems and their rights as children. It has also resulted in some reported benefits for children themselves, for example in promoting well-being and resilience, including self-esteem, self-efficacy, self-control, sensitivity to the perspectives of others, hope for the future, democratic decision making, and active citizenship (Malone & Hartung 2010). A dynamic interaction between researchers, policy makers, advocacy groups, and funding institutions, within developing as well as developed nations, is essential to ensure that priorities in child research are based on sound evidence and remain at the top of the international development agenda.

The articles in this volume represent the broad spectrum of research that is ongoing and necessary in relation to child health. Articles start from a focus on health promotion in the early years and turn to mental health in college students, the challenges of labels and accurate diagnoses, quality improvement initiatives in health care systems, children and parents’ experiences of rare and life-limiting conditions as well as an overview of health service use and planning and include international perspectives on some of these issues, including on the important problem of medical poverty.

We would like to thank all authors and the reviewers for their contributions to this issue. Special thanks are also due to all who helped with proof reading and to AAD for providing the design and layout. Continuing our recent attempt to make the Digest more sustainable, authors have been offered to make a contribution towards printing costs to facilitate greater distribution and dissemination of the Digest to appropriate audiences. We thank everyone who contributed.

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References

Introduction

It is now well-acknowledged that the foundations of lifelong health are built in early childhood (Center of the Developing Child at Harvard, 2010). Internationally, there has been a growing body of evidence highlighting the importance of early life experiences for future health and well-being (Barker, 1994; Barker, 2000; Marmot 2010). At a national level, the Growing up in Ireland Study has identified key public health issues that are emerging by age three, including obesity (ERSI, 2011) and significant health inequalities across a range of indicators which persist into later childhood (ERSL 2013). Early childhood professionals who work directly with young children and their families in early childhood settings on a daily basis have a significant role to play in promoting children’s health and well-being. Drawing on current literature and recent policy developments, this paper aims to highlight the importance of early childhood practice in promoting child health and well-being and documents some of the key principles that are stressed when working with Early Childhood Care & Education (ECCE) degree students.

The first key principle is that early childhood experiences matter. For early childhood educators of the future, recognising their role and adopting an evidence based approach to their practice needs to be instilled during their undergraduate studies. This paper stresses the need to encourage students to identify broader definitions of health and well-being, beyond the traditional confines of health and safety practices. The evidence tells us that early life experiences matter and so do ECCE students as the future early childhood educators and advocates for children (Center of the Developing Child at Harvard, 2010). The early childhood setting can play a vital role in providing an environment that enables healthy choices and experiences, promotes well-being, identity and belonging, communication and exploring and thinking (NCCA, 2009).

An ecological approach to child health and well-being

A key principle for ECCE students is to recognise the importance of an ecological approach to promoting health and well-being.

Adopting an ecological approach to child health recognises the many different factors in children’s lives that influence their health and well-being, such as family health and relationships, poverty, early childhood settings, local communities, social capital, cultural perspectives and national and international policy, amongst others. This universal societal approach is advocated in Irish policy through Healthy Ireland. During their undergraduate ECCE degree, students’ understanding of the concepts of health and wellness develops with their increasing theoretical knowledge and understanding compounded by their practicum placement experiences. Students begin to appreciate that many different factors in children’s lives influence their health and well-being and consider how factors such as poverty, housing and family health and relationships may influence children’s health and well-being and how these factors may exist or work together to influence children’s lives. It is important, therefore that students consider the broader determinants of health. This can be achieved through investigating how social inequalities in health are evident in Ireland, drawing on Growing up in Ireland data for example (ESRI, 2013), or using key examples such as low birth weight, obesity and the health status of children within the Traveller community and recognising the complexities of health promotion.

An evidence based approach: Practitioners as researchers

A key principle for ECCE students is to recognise the importance of an ecological approach to promoting health and well-being.

Looking to evidence helps to avoid complacency, while engaging in reflective practice is a marker of professionalism. This includes asking questions such as, with regard to consideration of infant sleeping position, for example, why it is recommended to put babies to sleep on their backs and what are the other factors that may reduce the risk of Sudden Infant Death Syndrome. It is important that ECCE students question and think as researchers, exploring and understanding the ‘whys’ so that they can make informed decisions in their practice. They may also be asked advice from parents in relation to topics such as immunisation, so having a clear understanding of the evidence is important. Students also engage in small scale research to develop these skills further and to transfer such skills to their future practice. Other considerations need to be given to questions such as how the ECCE setting can facilitate mothers to continue breastfeeding, how the ECCE setting can maximise indoor and outdoor environments for learning and well-being, addressing the Aistear theme of well-being (NCCA, 2009), gender differences in how early childhood educators encourage different types of play, physical activity and rough and tumble play, as just some examples. In terms of obesity rates at age five, significant gender differences are for example apparent with higher rates in girls (ESRI, 2013).

Advocates for children’s health and well-being

Another key principle is that students are encouraged to see themselves as advocates for children’s health and well-being for now and into the future.

ECCE students are encouraged to recognise their future role as early childhood practitioners within an ecological model along with the influence they have in promoting the health and well-being of children in their care, as well as the children’s families, local communities, and the role they have in creating links, lobbying local councils and at a national level to advocate for young children so that the factors that influence their health and well-being will be prioritised to ensure that every child has the best start in life (Marmot, 2010).

Siolta, The National Quality Framework for Early Childhood Education (CECDE, 2006) established 18 standards of quality. Standard 1 considers the rights of the child. From a social justice and moral perspective, all children should have the right to a healthy childhood, as also specified in Article 24 of the UN Convention on the Rights of Child (1989). To justify the importance of the earliest years of life, we sometimes tend to adopt a futuristic perspective, the notion of well-becoming rather than well-being. For example, the World Health Organisation (2008) notes that, “Children represent the future, and ensuring their healthy growth and development ought to be a prime concern of all societies”.

We often cite literature highlighting the long-term implications of child health and early life experiences into adulthood. However, it is important that for ECCE students, the focus is not just from such a futuristic perspective but addresses the fundamental rights of the child. Health and well-being are specifically covered under Siolta’s Health and Welfare and Environments standards, yet one could argue that all the quality standards relate to child well-being in some capacity.

Key developments in early childhood policy and practice

Another key principle is that best practice should reflect current policy and legislation.

Within the field of early childhood practice in recent years there have been some significant developments. Aistear, the early childhood curriculum framework in Ireland (NCCA, 2009) was launched in 2009. Designed for children from birth to six, Aistear adopts a continuum of learning across four key themes: Exploring and thinking, Communication, Identity & belonging and Well and Being (NCCA, 2009). The themes are interlinked with the ultimate aim of promoting confident and competent learners. The theme of well-being has four key aims.
Aim 1: Children will be strong psychologically and socially
Aim 2: Children will be as healthy and fit as they can be
Aim 3: Children will be creative and spiritual
Aim 4: Children will have positive outlooks on learning and on life

Within each aim there are six further learning goals for children to meet ‘in partnership with the adult.’ As a curriculum framework, Aistear is designed to be broad and meet the needs of all children, in all early childhood settings across infancy, preschool and into primary school. It can therefore be challenging for students and ECCE practitioners to decipher how best to fully address these key aims and learning goals. The theme of well-being moves beyond the traditional notion of health and safety. Mealtimes for example should incorporate a healthy eating policy but should also be valued as an important daily social event, providing many potential learning opportunities and scope for building relationships with children and adults. Children and adults eating together in respectful and aesthetically pleasing environments, growing and preparing food or table settings etc and encouraging positive attitudes to eating. Similarly, indoor and outdoor environments should be maximised to engage children in physical activity, both adult-guided and child-initiated. These can include traditional games, yoga and obstacle courses that help to develop fundamental movement skills.

ECCE students need to recognise that not only is it important that children grow up in a physically safe environment, children also need a safe and secure emotional environment. Relationships in early childhood can have lifelong implications for emotional health, stress responses, competency of the immune system and appropriate health-related behaviours (Center on Developing Child at Harvard, 2010). The wellness of children is strongly influenced by the wellness of those around them, parents and caregivers, families, ECCE practitioners, local communities and of society at large. Students are therefore encouraged to focus on their own well-being and there are a range of resources and supports available to them.

The Childcare Regulations (GoI 2016) provide the legislative framework to ensure that basic standards of quality care are provided for young children and have developed beyond addressing just the static environmental factors traditionally associated with health and safety. As adults working with young children, it is essential that every effort is made to anticipate and eliminate potential dangers but to also provide a challenging and stimulating learning environment. This can be a difficult balancing act as children need physical activity to promote their physical development and the questions are asked of the students whether there is an overemphasis on safety. Similarly, in terms of hygiene there are concerns that it is becoming too clean, trying to prevent the spread of infections in ECCE settings with standard precautions but risking creating too clinical an environment for young children and their developing immune systems.

Significant developments to promote well-being for all of our youngest children

Another key principle is that the health and well-being of children should matter to all in society.

In 2010, the government introduced the free preschool year for children. The scheme was extended to two years for each child in 2016 and uptake is now almost universal, engaging almost 5000 preschool services. The DCYA (2016) published the Diversity, Equality and Inclusion charter and guidelines for early childhood care and education, which links with promoting the well-being of young children in ECCE practice. The Access and Inclusion Model (Aim, 2016) was established to promote an inclusive culture within early childhood, reiterating the ethos of promoting the health and well-being of all children. It is also paramount that those working in related fields can recognise the potential of

of the early childhood setting in promoting health and well-being. Through AIM, early childhood educators are working with other professionals in the field to promote the well-being of all children. For ECCE students today, through recent developments in policy and legislation the landscape is changing to give more consideration to the well-being of young children.

Conclusion

It is essential that early childhood practitioners working directly with young children and their families have a fundamental understanding of the many different factors that determine children’s health and well-being and an understanding of how to promote the health and well-being of young children in the early years of their lives that is evidence-based. This understanding is instilled in ECCE students during their undergraduate education and this paper highlighted some of the key principles addressed with students. Providing a clean, safe and nutritious environment is important but if the foundations of health are to be addressed, children need to be exposed to positive, healthy experiences in environments that enable healthy choices, both indoors and outdoors. Children need environments that stimulate and challenge, that encourage positive relationships, address diversity and truly promote inclusion and positive health for all children. This culture needs to be nurtured in order to maximise the potential of the ECCE setting in producing an optimal environment for children during their most formative years in which their health and well-being can develop and thrive.

References


The economics of school-based interventions to prevent childhood obesity

Dominika Batorova, Regien Biesma and Jan Sørensen

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Introduction

Physical activity is important for good health, quality and longevity of life. The World Health Organisation (WHO) recommends that adults are physically active for at least 30 minutes daily and children at least 60 minutes daily (World Health Organisation, 2010). Epidemiological studies show that people who do not achieve these recommendations are at higher risk of developing hypertension, obesity, diabetes, cardiovascular diseases, certain forms for cancer and mental illnesses (Andersen et al., 2000). Life expectancy for inactive people has been estimated to be three to five years shorter than for physically active people; they use more healthcare services, have more frequent and longer absence periods from work and reduced health-related quality of life (Juel et al., 2008).

In modern societies it appears difficult to achieve a sufficient amount of physical activity for many people (Department of Health & Children Health Service Executive, 2014). Recent surveys have indicated that there are large proportions of inactive people particularly among children and young people, and this is a common trend in many countries (World Health Organisation, 2017). An active lifestyle accompanied with good dietary habits may be an effective way of avoiding overweight and obesity (Steinbeck, 2001). Unfortunately, the proportion of people who are overweight or obese has been increasing in many countries. This also applies for children and may pose a real threat for public health (Lobstein et al., 2004).

Public health interventions to prevent and reduce obesity are difficult to implement. Although short-term weight loss may be achieved through increased activity and restricted diet, long-term weight control is more challenging to achieve (Mead et al., 2017; Al-Khudairy et al., 2017, Wang et al., 2015). Many clubs, charities and private organisations provide a wide range of opportunities for young people to engage in an active and healthy lifestyle. However, such organisations typically attract only certain segments of the general population. Schools may have better and more effective means of reaching out to all children and support them with forming healthy habits. A wide range of school-based programs have been developed worldwide, and many of them have been evaluated to document their ability to achieve recommended physical activity levels, weight control, and prevent or reduce obesity.

However, school-based interventions have opportunity costs (Cawley, 2010), which implies that when a decision to provide school based intervention had been made, the resources cannot be used for something else. In other words, school time used on physical activity cannot be used for other types of teaching. This may not be a problem if the programme integrates physical activity into other teaching activities and achieve several teaching objectives. Evidence suggests that physically active children are more motivated and perceptive to traditional forms of teaching, so increased physical activity may actually improve the outcomes of the teaching (Haapala et al., 2017). The opportunity cost may be lower in school-based physical activities such as walking or biking to school, or activity during the breaks or afterschool. Nevertheless, it requires resources to integrate more physical activity into schools’ daily routines. These resources relate to schools, teachers, children and their families.

There exist comprehensive general frameworks for economic evaluation of physical activity and obesity prevention interventions (Edwards et al., 2013, Wolfenstetter, 2011). The general principles attempt to specify the costs related to the provision of the intervention and relate these costs to the major outcomes from the intervention. The outcomes relate to the children who become more active, and the improved health and other benefits that arise. To fully capture the costs and benefits of childhood obesity interventions, a long-term lifetime approach should be applied (Wolfenstetter and Wenig, 2011). Therefore, the use of modeling techniques in assessing this type of interventions may be unavoidable (Buxton et al., 1997).

The aim of this paper is to describe how economic evaluation can be applied to school-based interventions to prevent and reduce obesity. We use a recent Canadian study that promotes active living and healthy eating in schools as an illustrative case.

Illustrative case study

This study assessed the long-term health and economic impacts of a school-based health promotion programme called APPLE Schools (Ekwaru et al., 2017). The intervention involved School Health Facilitators promoting healthy eating and active living among students, their parents, school staff and other stakeholders for a period of two years. These health facilitators were employed at ten “intervention” schools. The evaluation focused on ten-year old children and their two-year development in weight and height as compared to similar students from 148 randomly selected “control” schools (Fung et al., 2012).

The economic evaluation of the intervention was devised as a long-term model-based assessment where the impact of the intervention was described in terms of changes in weight status, risk of chronic diseases, and quality-adjusted life years (QALY) for the cohort of 10-year olds until they reached the age of 85 years. Based on collected data for the intervention and control groups, two-year transition probabilities for three weight categories (normal, overweight and obese) were estimated. The two-year outcomes were based on observational data, and were expressed as change in weight categories due to the intervention.

To extrapolate these outcomes three scenarios were used to describe the weight development during the subsequent eight years after the end of the intervention. Children could either maintain the effect; they could continue with the improved effect for two more years, or the effect could decline by a specified annual rate. At the end of this eight-year period it was assumed that the weight category would remain unchanged from 18 years until 85 years.

For the lifetime of the ten-year olds, health states with thirteen chronic diseases, no-chronic disease and the dead state were modelled for the three weight categories (total of 43 annual states). The empirical basis for these models included national population statistics (mortality), survey data (weight status), and epidemiological studies reporting on relative risk ratios, disease prevalence, and health related quality of life. This complex transition model was then used to estimate the incremental effect in terms of prevented life years with excess weight and chronic disease and gain in QALYs for the three scenarios relating to the weight development after the intervention.

The study also considered the cost of the health facilitators for the intervention schools, and could therefore assess the cost-effectiveness of such interventions given a specified value of the included outcomes. This model-based approach enabled a wide range of sensitivity analyses of key assumptions applied in the model.

Challenges for Economic Evaluation of Childhood Weight Interventions

Although the study has generally high methodological quality, a number of methodological challenges for economic evaluations can be identified from the study.
The key assumptions applied when developing the model should reflect the cause-and-effect relations of the analysed interventions and the underlying biological process of the condition in question (Philips et al., 2006). The underlying conceptual assumptions for evaluating lifetime consequences of APPLE Schools were based on evidence from several longitudinal studies showing that childhood obesity tracts into adulthood (O’Brien et al., 2007).

The effectiveness of the intervention was based on ecological change in the weight status distribution of the students attending APPLE Schools relative to those attending control schools at the follow-up time. The effect of the program at individual level was not determined. Ideally, data on effectiveness of an intervention should be based on a randomised controlled trial or a prospective cohort study with controls where the individual change in behavior and weight is observed for a longer period of time. With no empirical evidence on the long-term effects of a specific intervention, it is important to understand the motives and mechanisms for change and ability to maintain the new behaviour in order to make reasonable assumptions about the long-term effects. In the current study, three different sustainability scenarios were applied. The authors were not explicit about the assumptions made on the sustainability of the effect even though these assumptions are of crucial importance in regards to the study results.

Ideally, the broad societal perspective including all costs and benefits no matter when and where they arise should be applied (Wolfenstetter and Wennig, 2011). However, a narrower focus is often taken to ease the complexity of the evaluation and to inform decision makers with specific budget responsibilities. Analyses with too narrow a perspective may, however, fail to include important consequences, so both evaluators and users of evaluations should be aware of limitations of such methodological choices. In the present study, the school system’s cost perspective was applied, which was justified by the publicly funded education system in Canada. This choice led to an omission of some important aspects of the intervention, such as potentially reduced use of healthcare and social resources and increased contribution to the labour market as a result of intervention. Additionally, since the intervention involved engaging children, their parents, school staff and other stakeholders, it may have had social diffusion effects into other population groups, and these effects could also have been accounted for in the study.

Another major challenge in the conduct of economic evaluations of preventive interventions is the appropriate identification and measurement of their benefits. In the described study, only the health gains in form of the reduced incidence of a specified set of obesity-related chronic diseases and mortality as a result of changes in weight were considered. However, positive changes in dietary and physical activity behaviors could be expected too. The health benefits that may arise from improvements in health awareness, self-efficacy and leadership as a result of prevented psychosocial consequences including low self-esteem, social alienation, discrimination and associated mental health disorders that can lead to a poor health-related quality of life (Davis et al., 1993, Davis and Christoffel, 1994, Davis et al., 1999) were not explicitly considered.

Moreover, the underlying assumption that the intervention will produce health gains only if it results in changes in weight status can also be challenged. There is evidence showing that other pathways of improving health through increases in physical activity, independent of changes in weight, exist (Puder et al., 2011). On the other hand, there are also some health risks inherent in engaging in higher levels of physical activity in form of injuries (Warsh et al., 2010). Other ‘negative’ effects of the intervention may be the unrelated healthcare costs that may arise from extending people’s lives. These consequences of the intervention were not considered in the study.

Finally, applying a generic measure of health benefits including both the quality and the quantity of life lived in form of quality-adjusted life years (QALY) is a recommended strategy in economic evaluation of prevention interventions. However, there is no consensus on how health-related quality of life should be defined and measured in paediatric populations (De Civita et al., 2005). In the current study, for every year lived with excess weight, obesity or chronic disease, a decrement in health utility scores was assigned to the total QALY. The limitation of this approach is that the estimates of these decrements were obtained from two studies in which participants were 18 years of age or older, which might affect the validity of the estimated QALY.

References


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Reaching out in college
A mixed methods study of help-seeking among students in Ireland

Gillian Karwig, Derek Chambers, Fenella Ryan and Roisin Doolan
Introduction
ReachOut Ireland, in collaboration with the Health Service Executive’s National Office for Suicide Prevention (HSE NOSP) and the Irish Association of University and College Counsellors (IAUCC), recently published the report Reaching Out in College: Help-Seeking at Third Level in Ireland (Karwig et al, 2015). The study explored the most likely sources of information and support for student mental health and wellbeing, with a focus on both e-mental health (use of the internet and technology for mental health information and support), and current college supports and services.

Methodology
A mixed-methods approach was undertaken for this study. An online survey was developed following a review of relevant literature and existing surveys, and a brief pilot phase; the survey link was subsequently circulated to students in participating colleges. The survey comprised 30 items across three sections: i) Demographics/basic information; (ii) Students’ views and use of various supports and services; and (iii) Students’ mental health.

Additionally, four focus groups were hosted with students. To ensure representation of views from different student ‘types’, the groups were open to any gender, and separate groups were hosted for first-year and final-year students. Each group had a duration of approximately one and a half hours. The groups were audio-recorded and transcribed, following which the transcripts were coded using thematic analysis (Braun and Clarke, 2006).

Survey results
In total, seventeen third level institutes participated in the online survey. Following omission of students who did not respond to any survey questions beyond the online consent form, the final survey sample included 5,556 students. The majority of respondents were female (61%), Irish (85%), and aged between 18–22 years (60%).

<table>
<thead>
<tr>
<th>Agree/Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental health information on the internet can be unreliable</td>
</tr>
<tr>
<td>Using the internet/technology for mental health information and support can allow for anonymity, privacy and confidentiality</td>
</tr>
<tr>
<td>I'd prefer to talk with someone in person about how I'm feeling, rather than with someone online</td>
</tr>
<tr>
<td>There is a vast amount of valuable mental health information available online</td>
</tr>
<tr>
<td>Online counselling from a professional can be just as effective as face-to-face counselling</td>
</tr>
<tr>
<td>There can be harmful discussions about mental health in forums, social networking sites or discussion boards</td>
</tr>
<tr>
<td>I'd be more likely to use online than face-to-face supports, if available from the college counselling service</td>
</tr>
</tbody>
</table>

Table 1: Students’ responses to statements regarding attitudes towards e-mental health

Attitudes towards e-mental health
Students were asked to indicate their level of agreement with statements reflecting various attitudes towards e-mental health. Table 1 presents results pertaining to the response options ‘agree’ and ‘strongly agree’:

The above results suggest that students hold diverse attitudes towards e-mental health. For example, while seven out of ten students agreed that there is a vast amount of valuable mental health information online, over half of students (54%) agreed that online information can be unreliable. Additionally, although the majority of students (81%) agreed that mental health discussions on online platforms can be harmful, a similar proportion (84%) also acknowledged that e-mental health can afford confidential and anonymous information and support.

Focus group results
Four focus groups were hosted with students, across two colleges (one university and one Institute of Technology). To ensure that the focus groups were representative of the student body, the groups were open to students of any gender and from any course, and separate groups were organised for first-year and final-year students within each college.

A total of 33 students participated across the four groups. The majority of participants were represented by females (27 students), Irish students (29 individuals), those aged between 18 and 22 years (27 students), and those studying at undergraduate level (31 students).

Following thematic analysis, two strong themes emerged: ‘mental health’ as a negative concept; and, ‘changing the narrative on mental health’.

Theme 1: ‘Mental health’ as a negative concept
Responses to the term ‘mental health’ during the word association exercises at the beginning of each focus group suggested that students’ understanding of mental health was predominantly deficit-based. Specifically, while a number of positive words were noted (including ‘universal’, ‘wellbeing’, ‘happiness’, ‘promotion’ and ‘awareness’), in addition to more neutral terms (such as ‘brain’, ‘thoughts’ and ‘mood’), focus group participants primarily reported words which were negative or which pertained to mental health problems. Indeed, one student noted that ‘mental health = a problem’, while others noted ‘people needing help’, ‘illness’, ‘difficulties’ and ‘disorder’. ‘Depression’ was the word most frequently reported during the exercise and was noted within three of the four focus groups, including seven students in one group alone. Additional negative words referred to particular mental health issues, such as ‘addiction’, ‘stress’, ‘anxiety’ and ‘suicide’; other words - ‘taboo’, ‘sensitive’, ‘stigmatised’ and ‘discrimination’ - suggested that the topic of mental health is not openly discussed. References to ‘counselling’ and ‘therapy’ were also rooted in mental health as a negative concept.

Theme 2: Changing the narrative on ‘mental health’
Notwithstanding the somewhat narrow and negative conceptualisation of ‘mental health’ noted throughout the focus groups, students discussed the importance of increasing awareness of a broader understanding of mental health amongst the wider student population.

For example, when asked whether colleges should refrain from using the term ‘mental health’ when referring to or naming relevant events and campaigns on-campus, it was suggested that ‘mental health’ could be used – if colleges cultivated an awareness of a broad understanding of the term in parallel. As noted by one of the students (who had previously stated that mental health sounds like a negative term)

“rather than kind of keeping on using it [the term ‘mental health’, without clarification], you could do something that lets people know that mental health isn’t just about stopping depression and helping people with anxiety, it’s also just being happy… so just kind of clarifying it” (FG3).
Survey results

The importance of increasing awareness of a broader (and more general) interpretation of mental health was emphasised by another focus group participant, who noted that she had previously equated the term ‘mental health’ with ‘mental illness’, by stating that ‘it sounds silly but people don’t – like I didn’t even know myself, mental health or whatever, you’d think of mental health as just mental illness so it wasn’t until I was doing Social Care myself that it was brought around that everyone has mental health, we all need to look after our mental health...’ (FG4).

Recommendations and discussion of findings

Traditional support services on-campus are valued by students and should be appropriately staffed and resourced. This is evidenced by the following findings:

- The Student Counselling Service and Student Health Service represent the services on-campus most likely to be used by students (reported by 83% and 58% of survey respondents respectively). Eighty-seven percent of students also agreed that ‘It’s reassuring to know that there is a free counselling service in college.’

- The Student Counselling Service is trusted: students are significantly more likely to avail of online counselling if specifically offered by their counselling service on-campus and are more likely to avail of Student Counselling than seek help from an external counsellor off-campus.

Students should be regularly provided with visible, engaging mental health information. This recommendation is supported by the following findings:

- Information should detail and explain the means to access the range of resources, supports and services available to students (on-campus, off campus and online). Information should also detail ways in which students can mind their own mental health and support others, given that 74% of students reported being likely to seek help from a friend.

- The vast majority of survey respondents (85%) reported being likely to go online when seeking information related to mental health and available supports and services; however, 54% also agreed that ‘mental health information on the internet can be unreliable’. Students should therefore be provided with quality mental health information online.

- Students in focus groups reported that online information provided/signposted by their college would be perceived as reliable. In particular, students suggested that the inclusion of an online mental health ‘section’ within their student portal would be valuable. Use of social media to provide mental health information in an engaging manner was also suggested, representing an opportunity for Students’ Unions to communicate information to students.

- Online mental health information that is provided to students within their college site should be user-tested, to ensure that they are likely to engage with the material.

Colleges should cultivate and promote a culture of positive mental health and help-seeking on-campus. The following findings elaborate this point:

- Mental health should be framed as an integral part of everyday life, and as a concept that does not pertain to mental health problems alone. As one student suggested, it is important that colleges ‘...make more awareness of even that term [mental health], that we all have a level of mental health, it’s not only then if you’re depressed or something’.

- Fostering a culture of positive mental health should encompass a whole-college approach to mental health promotion, with the provision of visible, engaging mental health information, hosting skills-based mental health workshops for students and, as suggested within focus groups, a lecture for all students on the topic of mental health and supports and services on-campus.

Colleges should audit and evaluate all resources and services currently being provided to students, including online resources.

- Evaluation should relate to the uptake and use of services, outcomes of service provision and satisfaction with service provision. Such information should be shared among colleges, to increase understanding of service provision at national level, and to inform future service development.

- Evaluation of resources and services provided on-campus is in keeping with Action 7.4.4. of Connecting for Life: Ireland’s National Strategy to Reduce Suicide 2015–2020 (Department of Health, 2015): ‘evaluate innovative approaches to suicide prevention, including online service provision and targeted approaches for appropriate priority groups’. This action specifically references ‘third level institutions’ as key partners. Finally, colleges should consider developing a system for information provision and referral of students to appropriate supports on-campus. This could involve a comfortable drop-in space on-campus or an online programme or screener that provides feedback to students on what to do or where to go. There is currently a gap between mental health need and knowledge as to how to access supports, despite a considerable range of supports being available. The findings of this study can support and inform practical strategies aimed at bridging that gap.

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References


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Gillian Karwig is training as a clinical psychologist through the Trinity College training scheme and previously worked as a researcher with ReachOut Ireland. Derek Chambers is Acting CEO of ReachOut Ireland, prior to which he worked in suicide prevention policy. Fenella Ryan is an Economics graduate and she has worked as a researcher with ReachOut Ireland since 2010. Roisin Doolan is a Health Promotion graduate with extensive experience of youth engagement through career experience with ReachOut in both Ireland and Australia.
ADHD, trauma and neglect
How do we prevent children who are in the child protection system from being misdiagnosed with ADHD?

Laura Hanbury
Introduction

Attention Deficit Hyperactivity Disorder (ADHD) is a very prevalent and common neurobehavioural disorder in children and adults. It is considered to be a developmental disorder and is recognised when children display inappropriate levels of hyperactivity, impulsivity, and inattention (American Psychiatric Association, 2013). It is now the leading diagnosed health condition for children in western countries and is now reported to have a worldwide prevalence of anywhere between 1% to 18% (Polanczyk, de Lima, Horta, Biederman and Rohde, 2007; Spitzer, Schragger, Imagawa and Vanderbilt, 2016). Whilst rates in Ireland tend to be lower, there is a feeling from some that numbers are on the increase (irishexaminer.com, 2013). For the purposes of this article, it is important to note that the rates of diagnosis for children within the child protection system are up to three times higher than that of the general population (Klein, Damiani Taraba, Koster, Campbell, and Scholz, 2015; McMillen et al., 2005; Sonuga-Barke, Daley, Thompson, Lever-Bradbury and Weeks 2015). As of yet, no study has been able to definitively establish why this is so. However, a number of theories have been put forward by researchers and clinicians (Howe, 2010; Panzer and Viijoen, 2003; Tarver, Daley and Sayal, 2014; Thapar, Langley, Asherson and Gill, 2007), which include that the behaviours perceived by professionals to be ADHD could be something else entirely.

Methodology

The following literature review was undertaken to explore the link between certain childhood adversities and the misdiagnosis of ADHD in children within child protection systems. It was conducted using an extensive search and data analysis of literature and data (using Google Scholar, ResearchGate, Academic Internet Journals and Kent University Library Systems?) which relates to ADHD behaviours and brain development, child protection and the effects of childhood trauma and adversity.

ADHD and misdiagnosis

As we start to discover more about the presenting behaviours and after effects of childhood adversity and experienced traumas, a plethora of evidence is beginning to emerge which supports the view that both ADHD and certain experienced traumas will present an overlap in symptomatology. For example, those children who have experienced childhood neglect or emotional abuse can often display similar sets of behaviours and cognitive deficits that are also associated with ADHD. This makes it very possible for a child to be misdiagnosed as both conditions have the potential to mimic one another in their presentations (Haber, 2003; Handler and DuPaul, 2005).

Brain studies on ADHD and childhood trauma

In child protection cases where emotional neglect, early deprivation and relational trauma has been identified, these children have been reported to experience other mental health disorders such as anxiety, depression, and difficulties with sleep (Ouyang, Fang, Mercy, Perou and Grosse, 2008). Recent research has found that the same list of mental health disorders can also co-occur alongside ADHD (Verkuijl, Perkins and Fazel, 2015). Indeed, when we compare certain brain development studies for both ADHD and child maltreatment, the results appear to show significant similarities in the areas of the brain that are affected by both ADHD and childhood trauma (De Brito et al., 2013; Kelly et al., 2013). These brain areas are responsible for emotional regulation, decision making, sequential and/or semantic memory and social and emotional processing (Nakamura et al., 2001; Onitsuka et al., 2004; Snowden, Thompson and Neary, 2004). Furthermore, Perry (2006) states that certain types of maltreatment can have a negative effect on a child’s ability to maintain concentration and attention, process sensory information and manage emotions. When such behavioural traits are also reported to be associated with ADHD, it is clear to see why a crossover in the diagnosis of the two conditions exists, especially when we directly compare the observed behaviours and cognitive functioning in these individuals. Short attention spans and lapses in concentration can be present at all times, but are likely to be noticed more in an environment where a child has to concentrate and sit for long periods or be around large groups of people where the behaviour of others can be misinterpreted.

Developmental trauma disorder

The Diagnostic and Statistical Manual of Mental Disorders (DSM) is published by the American Psychiatric Association and is currently the leading manual used by clinicians. Van der Kolk et al (2009) suggested that there is a real need for a reclassification in diagnoses for children who have been maltreated due to the considerable overlap in the presenting symptoms of ADHD and experienced ‘interpersonal trauma’. Interpersonal or ‘Relational’ Trauma is a term used to describe an event that a person experiences and/or is witness to whereby they become personally traumatised by doing so. Examples would be experiences when a child is sexually abused, witnessed domestic violence, or experienced ‘interpersonal trauma’. Such experiences can include (but are not limited to) domestic violence, physical, verbal and sexual abuse, neglect, the sudden loss or the feeling of abandonment and substance abuse. In a survey involving 1699 children, they found that many children who had experienced interpersonal traumas were ending up with a diagnosis of ADHD, as no clinical diagnosis existed which could successfully capture the true clinical presentations of these children. Van der Kolk and his team shared their findings with the group work advisers for the DSM and made a proposal to include a ‘Developmental Trauma Disorder’ (DTD) diagnosis for children and adolescents in their 5th edition of the manual. In the proposal, he stated that the current terms for ‘hyperactivity’ and ‘attentional’ problems were too generalised. Reference was also made to an increased likelihood that a child who has been through some form of interpersonal trauma will instead be diagnosed with ADHD. Van der Kolk’s proposal for the inclusion of DTD was unfortunately rejected by the group. Instead, we saw the newest publication of the manual in 2013 (DSM-5) widen its criteria to meet a
diagnosis for ADHD. Therefore, it is now possible for mild and moderate presentations of ADHD behaviours to be eligible for a diagnosis. This raises concerns in the field of child protection and many worry that there is now a heightened risk of misdiagnosis. It means that many young people who are experiencing adversity could slip through the net (Van der Kolk et al, 2009).

The diagnostic pathway

At present, clinicians seem to be in command of the diagnostic process for ADHD, when in some cases, they may not be in the best position to establish the cause of the presenting behaviours. Making a diagnosis of ADHD in the UK and Ireland relies on large pieces of subjective information. This is collected via parent/teacher feedback on observed difficult behaviours (that can greatly be influenced by personal feelings), and screening tools (Conors, Sitarenios, Parker and Epstein, 1998; Goodman, 1997). Behavioural observations tend to happen in a clinical setting and not in the family home. In a scenario where a child has been maltreated, clinicians should pay careful attention to the direct observation of ongoing family dynamics and the relationships that the child has in their lives in order to rule out the presence of an experienced or ongoing trauma. It is therefore unfortunate that current clinical practice does not allow the time nor the flexibility to directly observe family interactions in the home environment. This could create an argument for child protection professionals to become more involved in the ADHD screening processes. At present, they are rarely asked to contribute their feedback or personal observations on family functioning and relationships, yet the identification of ADHD and childhood adversity is largely reliant on a professional’s skilful ability to gain a truthful and accurate picture of what life is like for the child in question.

Implications and conclusion

When substantial evidence suggests that the after effects of childhood trauma and ADHD has the potential to display similar difficulties in behaviours and cognitive shortfalls, why is more not being done to raise the awareness of this in the field of child protection and education? To receive a diagnosis of ADHD can be a life changing event for a child and their entire family, but if a misdiagnosis occurs, there could be catastrophic consequences. The most popular concern lies in the notion that a child’s physical health is being put at risk whenever they are wrongfully diagnosed with ADHD and given medication when they do not need it. This is indeed concerning, but perhaps what is even more shattering to imagine is the idea that no amount of medication is going to heal any previous trauma that the child may have been through. To miss a case of past or ongoing child maltreatment in favour of a wrongful ADHD diagnosis will affect the way an individual relates to the people around them and could create a higher risk for the child to develop further psychiatric difficulties in the future (McMillen et al, 2005). With so much at stake for the children and families involved in the diagnostic process, it is important that practitioners are able to distinguish between the two presenting conditions. Therefore, it is imperative that both areas are treated with an equal interest and are studied side by side.

In order to move away from what Thomas, Mitchell and Batstra (2013) refer to as the ‘clinical subjectivity’ of ADHD diagnosis, the knowledge base for professionals needs to improve. In cases where a diagnosis of ADHD is sought for a child who comes from a family where intergenerational traumas exist, practitioners should have the confidence to question the diagnostic pathway and suggest alternative investigative routes when trying to establish a cause for the challenging behaviours. This way, practitioners could then start to look at the presenting symptoms of a young person in the child protection system through an objective lens and ensure that better outcomes are achieved in the future.

References


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Improving patient flow in a nephrology department

Lisa Edwards


Thomas, R., Mitchell, G., & Batstra, L. (2013) Attention-deficit/hyperactivity disorder: are we helping or harming?. BMJ.


Author information

Laura Hanbury is a PhD student at Royal Holloway University as well as a Family Practitioner for Looked after Children. After completing her Masters in Advanced Child Protection at the University of Kent, her current work mainly focuses on the study of challenging behaviours and the dyadic communications that present in the relationships between children/ adolescents and their parents or foster carers.

Before completing her Masters and embarking on a PhD, Laura’s experience in the field of child protection and in the direct work with families and young people stretches over a period of 12 years. Laura specialises in the analysis of family dynamics and relational trauma.
Introduction

The national paediatric nephrology programme has evolved over the last 30 years to provide high class tertiary paediatric nephrology care to children with kidney problems in Ireland. Diagnosis with a kidney condition can be devastating and life altering for a child and their family. However, with support and careful specialised management, it is possible to maintain a good quality of life and plan ahead for renal replacement therapy as required. This planned approach must be delivered within an evolving health service and a changing society, while the focus should always centre on individualised care and a drive to improve the quality for the patient (Royal College of Paediatrics and Child Health 2011). This article is an overview of a quality improvement project. This initiative was undertaken as part of the criteria to complete a Diploma in Patient Safety the author undertook with the Royal College of Physicians of Ireland (RCPI).

Attendances at the specialist nephrology clinics are steadily increasing as it provides a national tertiary referral centre for nephrology. It also provides the only national paediatric renal transplant service for the care and follow-up for this cohort of patients is demanding and patient specific. The environment of clinic is not suited to children with kidney problems in Ireland. However, with support and careful specialised management, it is possible to maintain a good quality of life and plan ahead for renal replacement therapy as required. This planned approach must be delivered within an evolving health service and a changing society, while the focus should always centre on individualised care and a drive to improve the quality for the patient (Royal College of Paediatrics and Child Health 2011). This article is an overview of a quality improvement project. This initiative was undertaken as part of the criteria to complete a Diploma in Patient Safety the author undertook with the Royal College of Physicians of Ireland (RCPI).

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The drivers for this project evolved as learning grew and this was supported by Langely et al (2009) who found that developing ideas for delivering change often expand upon reflection and knowledge. This quality improvement initiative was driven by three primary drivers, which fed the wheels of the secondary drivers and outcomes. (Figure 1). These drivers were influenced around the areas of risk which were identified following completion of risk management forms.

<table>
<thead>
<tr>
<th>Primary Drivers</th>
<th>Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Restructuring of clinics</td>
<td>Reconfigure clinic codes and new/ follow up slots and numbers.</td>
</tr>
<tr>
<td>Appointments made</td>
<td>Team away day to discuss strengths, weaknesses of unit. To agree new consultant cover and clinic days.</td>
</tr>
<tr>
<td>Administration support to manage workload</td>
<td>Agree what is expected for professional communication among the team</td>
</tr>
<tr>
<td></td>
<td>Mandatory attendance at Thursday blood result meeting</td>
</tr>
<tr>
<td></td>
<td>Appointments confirmed, investigations booked</td>
</tr>
<tr>
<td></td>
<td>New documentation developed to capture activity within the clinic</td>
</tr>
<tr>
<td></td>
<td>Risk management forms to advocate for dedicated clerical support</td>
</tr>
<tr>
<td></td>
<td>Documentation showing follow up plan given to secretary-appointment made and posted</td>
</tr>
<tr>
<td></td>
<td>Patient attendance and details accurately captured on IPIMS system</td>
</tr>
<tr>
<td></td>
<td>Letters dictated and typed, filed and posted to GP in a timely manner</td>
</tr>
</tbody>
</table>

Table 1: Drivers for Improvement
Measures for patient safety:

To determine whether any changes made because of this project could be considered improvements, it was necessary to gather data and review the treatments and outcomes objectively. By correlating information over a four-month period, comparing patient attendances with appointments made by the end of the week, it was possible to develop a run chart and ascertain that the changes we implemented were positive and sustainable (Figure 2). Run charts give direction in delivering a change and ascertain if that change is an improvement.

Example:

The information to support the changes and collection of data was generated from the essential tool of a PDSA cycle (Plan-Do-Study-Act), a tool developed by Demming in the 1950s. In planning how to approach the change, carrying out a small test in change, studying the effect of this test and acting on any results, it breaks down the change process and makes success more achievable. The use of this tool was invaluable in breaking down tasks which seemed daunting and making them feel like small steps that could be achieved in a short space of time. By working through the cycle and going back to the drawing board to tweak the process from feedback, sustainable change was facilitated. The PDSA cycle addressed problems from leading a small test in change, studying the effect of this test and acting on any results, it breaks down the steps of change and makes tasks more achievable.

As in any team, there are some who resist change, especially some of the consultants who were reluctant to change their practice. This was a barrier that needed to be overcome early in the exercise. The identification of one consultant as a partner in this project was hugely important, both to the success of the improvement initiative and for the initiative instigating practitioner’s self belief and confidence in successfully leading this change initiative.

Results and discussion of project implementation:

The results of this project achieved significant improvements within the renal outpatient clinic. In relation to appointments, while the aim of 100% of patients receiving appointments by the end of the week was not delivered, it was an impressive result of 98%. Patients who did not get return dates however had a clear plan of care, and were likely awaiting a date for surgery, or another procedure. The impact for our department has been cathartic. The knowledge that a system is in place and works to improve patient safety and quality has given a sense of freedom from previous pressures and delivers what is needed in order to move forward as a national service and providing clinical governance and safety for service users.

Staff acknowledged that there was a real safety issue and agreed it needed to be resolved urgently. Through stakeholder mapping, key members of the team were identified who could work together to drive this change for improvement. Working with high interest or high influence members of the team, it was possible to share the ownership of this project so it became personal to staff and those involved in the project overall. Using the PDSA cycle, key members contributed to the development of documentation and clinic process in an inclusive manner through successfully breaking down the steps of change and making tasks more achievable.

As in any team, there are some who resist change, especially some of the consultants who were reluctant to change their practice. This was a barrier that needed to be overcome early in the exercise. The identification of one consultant as a partner in this project was hugely important, both to the success of the improvement initiative and for the initiative instigating practitioner’s self belief and confidence in successfully leading this change initiative.

Conclusions and recommendations

This project succeeded on many levels. It achieved an impressive 98% of patients receiving an appointment by the end of the week they attended, up from 64% previously, with a clear and concise plan for all patients and scans or investigations booked as needed. This has resulted in better patient flow and satisfaction from families and staff. Secondly it has improved how the team communicates and sets achievable

Figure 2: Run Chart Dec 2014 – April 2015
goals to further develop the service. It has also benefited the author as a project lead, personally, in professional growth and leadership development.

People should be aware that the steps in this initiative were small steps. Basic documentation and communication led to its success. No change is too small. Identifying key people and early innovators is vital. By keeping it relevant to the frontline and not complicating the point, people will participate. After presenting this at a Clinical Nurse Specialist meeting, other nurses have approached the author to see what they can take away to their area to improve care. One nurse has also signed up to do a course on Patient Safety and thus beginning a wider spread of change throughout the organisation.

References


Author information

Lisa was appointed Nephrology Service Coordinator in Temple Street hospital in 2016. Lisa is a registered general nurse from the Nightingale Institute, London and having worked in various specialties internationally, registered as a children’s nurse in Temple Street in 2005. Following qualification Lisa commenced as a staff nurse in the Nephrology service. In 2008 she took up a role as renal CNS and was responsible for patients requiring renal replacement therapies and transplantation. She managed a busy outpatient services and became involved in rare disease management, research and quality improvement. Lisa holds a H.Dip Adult nursing (Kings College London), H.Dip Paediatric Nursing(UCD), Cert Renal Nursing (DCU), Post-Grad dip Child and Adolescent health care (DCU), Diploma Patient Safety (RCPI) and is undergoing a MSc. Adv. Leadership(RCSI).

“You are on a Roller Coaster”

Families’ experiences of living with and caring for children with Mucopolysaccharidosis

Suja Somanadhan and Philip Larkin
Introduction
This paper draws from recent doctoral research completed by Somanadhavan (2016), which provided a deeper understanding of the lived experience of parents of children, adolescents and young adults with Mucopolysaccharidoses (MPS) in the Republic of Ireland. This research project was in collaboration with the Irish National Centre for Inherited Metabolic Disorders (NCIMD) situated at the Temple Street Children's University Hospital and University College Dublin.

General aspects of MPS and rare diseases
MPS is one of the many rare inherited metabolic conditions falling under category 3 of life-limiting conditions (Parini et al., 2016; Somanadhavan & Larkin, 2016). It is caused by the body’s inability to produce specific lysosomal enzymes (Giugliani, 2012; Parini et al. 2016). Children born with this genetic condition show no change at birth, but as it is a progressive disease, its effects start to show in subsequent years. Each MPS disorder is caused by the body’s inability to produce specific lysosomal enzymes involved in the degradation of glycosaminoglycans (GAG) (Giugliani, 2012; Muenzer, 2011, 2014). This specific enzyme deficiency results in an accumulation of large amounts of GAG, or complex sugar molecules in harmful amounts in the body’s cells and tissues (Giugliani, 2012; Muenzer, 2011). These results in progressive cellular damage, which in turn leads to an array of manifestations that worsen with age, and can affect multiple organ systems, leading to cognitive impairment and eventually resulting in severe morbidity and premature death (Giugliani, 2012; Kircher et al., 2007; Muenzer, 2014). Currently, there are seven different types of MPS (I-IV, VI, VII and IX), some of which are classified into a variety of subtypes due to their clinical and biochemical features. Except for MPS II, MPS is a genetic disorder inherited in an autosomal recessive pattern affecting both males and females (Giugliani, 2012; Muenzer, 2014).

MPS is classified as a “rare” or “orphan disease”, and all forms of MPS are included in the rare disease database (NORD, 2014). There is a disparity in the international definition of rare disease, with some definitions depending solely on the number of people living with certain diseases. The European Commission on Public Health (2011) defines rare disease as a life-threatening or chronically deliberating disease, mostly inherited. In EU countries, any disease affecting fewer than five people in 10,000 is considered rare. Many rare diseases of childhood are life-threatening and chronically debilitating, so living with a rare disease is an on-going challenge for patients and their families. There are more than 6,000 rare diseases, and 1 in 17 people will be affected by a rare disease at some point in their lives in the UK, and sadly 75% of rare diseases affect children (DOH, 2014; Rare Diseases UK, 2015) and 30% of children with a rare disease die before their fifth birthday (DOH, 2014; Rare Disease UK 2015). Most importantly, rare diseases do not only affect those diagnosed but also their families, friends, carers and society (DOH, 2014; EURORDIS, 2014).

There is a need for knowledge and information about the child’s condition and the importance of providing intervention options and appropriate service and care for children with rare diseases as well as their families. The UK Strategy for Rare Diseases (2013) highlighted the importance of engaging and involving patients and their families in research and how their input can improve both the quality and effectiveness of research. The Department of health in Ireland (2014) also highlighted, in the National Rare Disease Plan for Ireland (2014-2018), the essential need for respecting and incorporating patients’ rights and their voices into the policies and services that affect them. It also noted the importance of establishing a variety of research approaches to rare diseases, including qualitative healthcare research, building partnership with service users which aim to explore their day-to-day challenges of living with a rare condition.

Aim
The research aimed to obtain a deeper understanding of parents’ experience of living with and caring for a child, adolescent or young adult with MPS.

Methodology
A qualitative approach, utilising hermeneutic phenomenology informed by the philosophical constructs of Heidegger (1962), Gadamer (1978, 1998) and Van Manen (1978, 1996), was undertaken. Van Manen’s six research activities were used as a guide for data collection through serial interviewing and phenomenological data analysis. A purposively selected sample of parents (n=8) attending The Irish National Centre for Inherited Metabolic Disorders was invited to participate. In this research study, the researcher engaged with the parents through serial face-to-face interviews over a period of 17 months (August 2013-December 2014), each interview lasting for 1-2 hours.

Findings
The five ‘lifeworld existential themes’ proposed by Van Manen (2014, pp. 302) underpinned the analysis and expression of the data in this study. These five fundamental lifeworld themes referred to as existential space (spatially), lived body (corporeality), lived time (temporality), lived other (relationality), and lived things (materiality) and described the way humans experience the world. According to Van Manen (1997, 2014), these belong to an existential ground, by which all human beings experience the world, and can be differentiated but not separated from the lived world. Nine themes and 22 corresponding subthemes were identified during data analysis.

Discussion
In this study, parents’ experience of raising a child with MPS was reflected in some ways. The majority of families started their lived experience from the time they received their child’s diagnosis and this experience then impacted their life as a whole. They spoke about grief and loss reactions associated with receiving their diagnosis and living day-to-day with an incurable condition. They talked about their child’s quality of life (QoL), their healthy children’s wellbeing, and for some, the impact on their own physical and psychological wellbeing. They also reflected on issues of stigmatisation and isolation in their experience of living with a child with a rare disorder. Even though the impact of a child’s rare, life-limiting illness on parents has been explored in a number of studies (Hunt et al., 2013; Malcolm et al., 2012; Rallison and Raffin-Bouchal, 2012; Steele and Davies, 2006), this study is the first of its nature that has explored the experience of Irish parents living with and caring for a child, adolescent or young adult across the full spectrum of MPS diagnoses.

This study’s findings reflect the wider literature showing the impact of other types of life-limiting illness, which have also indicated how caring for someone with MPS can have broader effects on all dimensions of the family’s life (Hunt et al., 2013; Malcolm et al., 2012; Rallison and Raffin-Bouchal, 2012; Steele and Davies, 2006). The parents in this study described the dynamics of the relationship as both a relational family status (reflecting their immediate family and close friends in a supportive care capacity) and a non-relational position (indicating those in the healthcare system and services). Parents negotiated both simultaneously as they managed their daily caregiving. The realisation that their child was diagnosed with a disease with no available curative treatment was a shattering experience for the parents, who also faced challenges in managing relationships with their healthy children and others close to the child, including their parents. They indicated that they had a broad range of emotions associated with instability of caregiving expressed through
Parents of Children with MPS

Figure 1: Themes and Corresponding Lived Space (Spatiality)
Future is unknown
It is no man’s land You feel sad and you know that it is losing him out.

Lived Other (Relationality)
Living with MPS I have always remained positive We are always proactive in MPS It is a battle You are on a roller coaster
Living with a rare genetic disease World came crashing down You do feel guilty You feel sorry for him that he is losing out

Lived Body (Corporeality)
The stigma of a rare condition Features do stand out We don’t want him to be treated differently
It is all MPS but all different diseases Light at the end of the tunnel It was a double-edged sword

Lived Space (Spatiality)
Future is unknown It is no man’s land You feel like you are in a box and you can’t get out of it
Hospital vs Home Hospitals bring you back to reality You are in your own home and do your own thing Healthcare system is a revolving door

Lived Time (Temporality)
Experience of waiting You are left waiting, waiting and waiting It is like watching a time bomb
Tough road ahead Frequent flyer Live day-by-day

Lived Things (Materiality)
Things in their day-to-day life with MPS Over the phone diagnosis The internet out there can be a wonderful tool

Figure 1: Themes and Corresponding Lived Existential Themes Themeatic Area Sub-themes (Parent’s Expressions)
Lived Other (Relationality) Living with MPS I have always remained positive We are always proactive in MPS It is a battle You are on a roller coaster
Living with a rare genetic disease World came crashing down You do feel guilty You feel sorry for him that he is losing out
Lived Body (Corporeality) The stigma of a rare condition Features do stand out We don’t want him to be treated differently
It is all MPS but all different diseases Light at the end of the tunnel It was a double-edged sword
Lived Space (Spatiality) Future is unknown It is no man’s land You feel like you are in a box and you can’t get out of it
Hospital vs Home Hospitals bring you back to reality You are in your own home and do your own thing Healthcare system is a revolving door
Lived Time (Temporality) Experience of waiting You are left waiting, waiting and waiting It is like watching a time bomb
Tough road ahead Frequent flyer Live day-by-day
Lived Things (Materiality) Things in their day-to-day life with MPS Over the phone diagnosis The internet out there can be a wonderful tool

Feeling of sadness, loneliness as they struggle to cope with the illness, grief, and fear. Uncertainty and changes in their family dynamics. These findings are again consistent with literature on parents of children with other life-limiting conditions (Hunt et al., 2013; Malcolm et al., 2012; Ballarin and Raffin-Bouchal, 2012; Steele and Davies, 2006) life-threatening conditions (Muscarra et al., 2015; Pam, 2002), and chronic illness (Knafl and Deatrick, 2002; Rehm and Bradley, 2005; Ward et al. 2014). Equally consistent with the literature was the experience of parents who were accustomed to fitting in around their child’s increased demands, resulting from the progressive nature of the illness (Courtney, 2011; Lane and Mason, 2014; Malcolm et al., 2012). Parents described their evolving role of a parent to their child, and mothers acting as the principal care providers among those interviewed. Only one father was interviewed, although the invitation to participate was open to both parents, either together or separately. Fathers clearly play a significant role in these children’s lives, and take on a caregiving role, protecting, and providing care for their family (Davies et al., 2004; Davies 2013). However, the study findings are consistent with literature which shows that women continue to take on the role of caregiver primarily when a child has a life-limiting illness (Nicholl and Begley, 2012; Ouellet, 2009; Sawatzky and Fowler-Kerry, 2003). Consistent with the literature (Morris, 2001; Radcliffe et al., 2013), the joint interview in the study highlighted the shared nature of families’ experiences of caring for a child with MPS. It was noted in this study that the joint interview appeared to hold greater distress in expressing the experience of participants, compared to one-to-one interviews (Radcliffe et al., 2013; Sakellariou et al. 2013; Taylor and de Vocht 2011). Both participants reported that their experience was equal to a counselling session or as a therapeutic relief from their stress, but expressed a sense of limbo when the research interviews were completed. However, the purpose of the research interview was not intentionally offering any form of therapy (Lowes and Paul, 2008), despite the participant report. This study suggests that researchers should be aware of the qualitative therapeutic interview process and its possible benefits for the participants’ emotional wellbeing throughout the research process that is also mirrored in other literature (Heppner et al., 1999; Lowes and Lyne, 2006; Nelson et al. 2013).

Conclusion
This research study is the first of its kind to act as an initial enquiry, and generating knowledge through researching lived experience of Irish parents of children, adolescents and young adults with MPS. This study provided a voice to the parents of children with MPS, and in doing so will make their lives more understandable to the wider audience. It brings to light the uncertainty, sorrow, and everyday challenges faced by these families, and hopefully will improve the care and support for them through the many months and years of their child’s illness. Therefore, this study can inform practice and policy implementation for service providers with a clear vision of what better care for children, adolescents and young adults with MPS and their families. The knowledge generated here can be the foundation on which specific recommendations for policy, practice, education and research could be made. The findings of this study represented a clear vision of better care for children, adolescents, and young adults with MPS and their families. The knowledge generated here can be the foundation on which specific recommendations for policy, practice, education and research could be made. The findings of this study represented a clear vision of better care for children, adolescents, and young adults with MPS and their families.
delivery and partnership care for children with rare diseases and their families.

Please visit https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5057247/ to access research publication via open access.

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Improving the lived experiences and needs of children with Haemophilia through research

Leonor Rodriguez
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Introduction
This quality of life, exploratory study describes the experiences and needs of children living with haemophilia in Costa Rica. The World Federation of Haemophilia (WFH, 2012) defined haemophilia as a rare disease, which is an X-linked congenital bleeding disorder caused by a deficiency in the coagulation factor VIII in Haemophilia A and factor IX in Haemophilia B. Diagnosis and management can be difficult as complications occur including musculoskeletal issues, the formation of inhibitors and transfusion-transmitted diseases. Haemophilia impacts the diagnosed child as well as their families. Overprotective families can lead to anxious, dependent children with behavioural issues (Abali et al., 2014). Some children report low self-esteem, depressive symptoms and lower self-perception (Coppola et al., 2011) but overall the majority adapt to their illness successfully (Canclini et al., 2003) and can manage to live almost normal lives with the appropriate treatments (Chandy, 2005).

The Costa Rican health system is public and run by the Ministry of Health (Caja Costarricense del Seguro Social). According to international economic indicators, Costa Rica is classified as a ‘developing’ country; but the standards of haemophilia care and treatment are comparable to developed countries according to the World Federation of Haemophilia, as the social security system allows access to treatment for those who may not otherwise be able to afford it. According to Chandy (2005), children with haemophilia in developing countries can have specific characteristics due to limited resources and elevated treatment costs; however, it is possible for a child to live an almost ‘normal’ life with adequate treatment. Children can attend school, participate in sports and cope with mild bleeds. Evaluating Quality of Life (QoL) is a useful way to understand lived experiences and identify the needs of children with haemophilia. QoL scales can be used to determine the effect of treatments that impact on the quality of life for chronically ill populations (Bullinger and MacKesen 2004; Pollik et al., 2008).

Children between six and twelve years of age were selected for this study as this stage involves important advances in moral development, memory, knowledge and thinking processes, and children can provide an accurate description of themselves including comparisons with their social and cultural context and the impact of these in their lives (Papalia, Wendkos and Duskin, 2001). Individual differences and needs become more important and can have an impact on scholarly success (Papalia, et al., 2001). Williams and Chapman (2011) found that children with haemophilia have a heightened sense of being different and can be set apart from their peers and community because of the rarity of their illness. Young people were also aware of differences from their same-sex peers (Williams and Chapman, 2011; Dasi et al., 2016). Peers and classmates may require education about haemophilia to avoid peer rejection, while children with haemophilia may also benefit from social and self-disclosing skills (Williams and Chapman, 2011).

This paper describes the self-reported experiences and needs of children between six and twelve years of age with living with haemophilia in Costa Rica and the impact that the illness can have on their lives and their self-concept. This is the first study to be carried out nationwide on children with haemophilia in this country and can inform practice and policy in terms of how best to support children and their families.

Methodology
This was an exploratory quantitative study. A QoL Scale for children with haemophilia was designed and validated for the Costa Rican context. Items were informed by previous scales used in an international context1. Those items that were relevant to the Costa Rican context and were understandable for a child and their parents were included. An advisory committee including healthcare professionals and members of the Haemophilia Association validated the content of the questionnaires. The questionnaires evaluated children’s sociodemographic data, nuclear family, peer relationships, self-concept, social Likert scale. Open questions were included to identify children’s definition of haemophilia and their self-reported needs.

This study was approved by the Ethics-Scientific Committee at the University of Costa Rica. Potential participants were contacted by phone and the main researcher organised home visits at a date and time to suit families. Families completed consent forms and questionnaires at that visit. Children were given a certificate and gift for participation. Open questions were coded. Quantitative data was input into the social sciences software package SPSS. This paper is focused on the descriptive analysis of questionnaire data.

Results
Due to haemophilia being an X-linked disorder2, all children in this study (N= 32) were boys between the age of six and twelve years. 28 children had haemophilia Type A and four had Type B (Table 1).

<table>
<thead>
<tr>
<th>Haemophilia</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>A mild</td>
<td>9.4</td>
<td>3</td>
</tr>
<tr>
<td>A severe</td>
<td>75</td>
<td>24</td>
</tr>
<tr>
<td>A moderate</td>
<td>3.1</td>
<td>1</td>
</tr>
<tr>
<td>B severe</td>
<td>9.4</td>
<td>3</td>
</tr>
<tr>
<td>B moderate</td>
<td>3.1</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 1: Types of haemophilia

Children were asked to describe haemophilia. The majority described it as causing bleeds and bruises (31.3%), an illness of the blood (15.6%) and 28.1% said they did not know. Children were asked about their experience of bleeds: 21.9% were extremely bothered by them, 28.1% experienced very severe bleeds, though only 6.3% were confined to bed due to the bleeds.

<table>
<thead>
<tr>
<th>Treatment</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>By demand</td>
<td>53.1</td>
<td>17</td>
</tr>
<tr>
<td>Home therapy</td>
<td>6.3</td>
<td>2</td>
</tr>
<tr>
<td>Prophylaxis</td>
<td>15.6</td>
<td>5</td>
</tr>
<tr>
<td>Home therapy and prophylaxis</td>
<td>25.1</td>
<td>8</td>
</tr>
</tbody>
</table>

Table 2: Types of treatment

The majority of children (53.1%) receive treatment by demand (Table 2). In terms of treatment, the majority of children (93.8%) do not know how to inject themselves. Only 6.3% of fathers administered injections to their children compared to 40.6% of mothers. The majority of children receive treatment from a nurse (40.6%) and classified treatment as effective (96.9%).

Children’s perception of hospitals was generally positive (40.6%) though 18.6% were negative. Half of the children expressed upset at having hospital treatment and 81.3% disliked receiving treatment. The majority of children (90.6%) expressed trust in healthcare professionals.

Children were also asked about the level of perceived control over their illness. The majority of children (84.4%) reported having a medium to high level of control. Over half of them (53.1%) think they are informed about their illness, but 28% expressed no perception of control. The majority (62.5%) stated that haemophilia was part of their normal life, 22% did not think haemophilia was normal in their life. Importantly, 75% of children said they were not upset at having haemophilia and only 15% expressed upset.

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2 X-linked recessive inheritance is caused by a mutation in the gene on the X chromosome that causes the phenotype to be expressed only in males as they have only one X chromosome.
Children were also asked about their levels of perceived pain, 46% responded as having medium pain while 31% reported the highest level of pain. Some (40.6%) reported highest levels of fear of hurting themselves. The majority of children (56.3%) described being careful with their bodies. The majority (59.4%) felt strong and energetic yet 28% report not being able to participate in sports and games due to their haemophilia.

Regarding social relationships and supports, half of the children expressed the view that they could discuss haemophilia with friends, yet 28% disagreed. Most children had a best friend (65.6%) that worried about them and 43% did not feel different to their peers due to their haemophilia. The majority of children (84.4%) considered their parents overprotective while 65.6% reported a good relationship with them. Children generally felt proud of themselves (84.4%), content with themselves (56.3%) and considered they had good ideas (56.3%). However, some children (6.3%) disagreed with these statements completely. Children also mentioned perceived needs they had: treatment and availability of treatment (43.8%), scholarly performance (18.8%), participation in sports and extracurricular activities (15.6%), emotional needs (3.1%) and support and affection (3.1%). 15.6% of children reported no additional needs.

Discussion

The experiences of Costa Rican children with haemophilia are diverse. Most children report positive lives but some children had severe bleeds and a small number of children were confined to bed due to bleed intensity. This suggests that despite the availability of treatments, haemophilia is still a challenge in their lives.

Children defined haemophilia in a concrete way, focusing particularly on visible bleeds and bruises. Children were aware that they lack additional information on their illness. Previous research has identified that younger ill children usually lack knowledge about their own diagnosis (Del Barrio, 1990), as understanding abstract medical concepts like internal bleeds may be impossible without professional help (Williams and Chapman, 2011). It is therefore relevant to include children as information receivers with age-appropriate information and allowing them to express their concerns (Dasi, Ortuno, Cid-Sabatel and Barbero, 2016). Being able to provide accurate description of their illness and the treatment needed may save these children’s lives.

Children between six and twelve years do not self-administer injections and rely on others for treatment. They are still too young to be able to handle and apply treatment correctly; as they develop this skill, it may eventually make a life or death difference in an emergency situation. The majority of children trust medical staff and the treatment they receive. A small number of children are very unhappy at having to attend hospital because of their illness, suggesting that hospital visits can be disruptive and difficult. As previous research has identified, illness and treatment impacts on the quality of life of individuals (Bullinger 2004; Pollak et al., 2006).

Most children described haemophilia as a normal part of their lives, feeling happy and in control. A small group did not feel in control or described haemophilia as a normal part of their lives. About a quarter of children explained that haemophilia makes their life difficult and they may struggle to cope with their illness. This is in line with previous research suggesting that the majority of children adapt to their illness successfully (Canclini et al., 2003; Chandy, 2005) but some children may be in need of additional supports to adjust.

Regarding social supports, the majority of children talk to their friends about their illness and seem to have a ‘best friend’ that cares about them, but a small number did not. The majority of children described positive parental relationships. The majority of children described themselves as feeling strong, proud, content and healthy but a small number of children with haemophilia may struggle with self-perception, experiencing low self-esteem, which is in line with previous findings (Canclini et al., 2003) reported.

Children described some of their perceived needs which included better access to treatment and better outcomes in education and more play. Previous research has suggested that children with haemophilia can have minor deficits in school when they experience more than twelve bleeds per year (Coppola et al., 2011; Abali et al., 2014).

Conclusion

As previous studies have suggested (Chandy, 2005), children with haemophilia can live an almost ‘normal’ life with appropriate treatment. In this study, the majority of children reported good self-perception, emotional well-being and ability to cope with their illness. However, six children were identified as having a greater vulnerability and risk. These children had lower levels in the perception of haemophilia including their own level of knowledge, the control they have over their illness and their perception of haemophilia as normal in their lives. These children also scored lower in social supports and emotional well-being, describing feelings of sadness, being overwhelmed, bad moods, fear of bleeds and insecurity about their haemophilia. The majority of children seem to adapt successfully to their illness but a small number of children may be struggling and reporting a higher level of vulnerability which can have a negative impact on their quality of life. This suggests the need to approach health not as an exclusively biological issue but with biopsychosocial interventions and comprehensive care (Dasi et al., 2016). While this study provides a description of variables that characterise children with haemophilia in Costa Rica, this exploratory study did not determine the correlations or interactions between variables, which may interest future research on the field.

References


Making children resilient to poor health: Can the number of children in a household play a role? Evidence from India

Leonor is a Postdoctoral Researcher at the UNESCO Child and Family Research Centre. She has experience in health and clinical psychology working with families, children and young people that experience chronic illness and completed a Masters in Clinical and Health Psychology in her native Costa Rica. Leonor completed her PhD in the School of Psychology, NUI Galway entitled ‘Understanding adolescent adjustment to maternal cancer: A study of personal experiences and psychological factors that promote adjustment’. 


Introduction

Under-five mortality rate (per 1,000 live births) in India is staggeringly high (forty-eight) compared to developed countries (Ireland and UK- four) (World Bank, 2016). Such a high mortality rate is mainly because of avoidable causes, for example, pneumonia and diarrhoeal diseases account for fifty per cent of all deaths at ages one to fifty nine months in India (Million Death Study Collaborators, 2010). This clearly signifies lack of health care access in India.

This study attempts to understand the role played by the number of children in a household in making children resilient to poor health. This has been done by comparing the incidence of medical poverty in households with no child, one child, two children and three or more children, where medical poverty has been defined as a state when a non-poor household falls below the poverty line after incurring health expenses (Xu, 2005). The poverty line has been defined as subsistence spending. The household subsistence spending is the minimum requirement to maintain basic life in a society (Xu, 2005).

At present, very limited studies exist in the literature on medical poverty, also referred as the impoverishment effect (Kronenberg and Barros, 2014; Xu, 2005). This study does not just add to the scant literature on medical poverty, but rather this is the first study that attempts to associate medical poverty with the number of children in a household. This could indeed provide crucial policy suggestions for framing health care policies for the Government of India (GOI).

Data and methodology

This study uses consumer expenditure data (2011-12) collected by National Sample Survey Organization, India. The total number of households surveyed were 101,662 with approximately fifty-nine per cent in rural India and forty-one per cent in urban India (GOI, 2014a).

The incidence of medical poverty and the poverty line has been estimated using the methodology suggested by Xu (2005). The following steps have been followed:

1. Estimation of subsistence spending

1.1 Food expenditure share has been estimated as:

\[ \text{foodexp} = \frac{\text{foodexp}_h}{\exp_h} \]

1.2 Equivalent household size is generated as:

\[ \text{eqsize}_h = \frac{\text{hsize}}{\text{eqsize}} \]

1.3 Equivalised food expenditure is generated as:

\[ \text{eqfood}_h = \frac{\text{foodexp}_h}{\text{eqsize}_h} \]

1.4 The 45th and 55th percentile is estimated and a weighted average variable (\( w_{45} \)) of 45th and 55th percentiles is generated.

1.5 Poverty line is estimated as:

\[ \text{pl} = \frac{\sum w_k * \text{eqfood}_k}{\sum w_k} \]

1.6 Subsistence expenditure is estimated as:

\[ \text{se}_h = \text{pl} * \text{eqsize}_h \]

A household is considered poor when total expenditure is less than subsistence spending and can be written as:

\[ \text{poor} = \begin{cases} 1 & \text{if } \exp_h < \text{se}_h \\ 0 & \text{if } \exp_h \geq \text{se}_h \end{cases} \]

2. Impoverishement (medical poverty)

A non-poor household falls into the trap of medical poverty when it becomes poor after incurring out of pocket (OOP) health expenses. Health expenses include both institutional (inpatient) as well as non-institutional expenses (outpatient). Let poor_medical be the variable created to reflect poverty impact of health payments. It takes the following values:

\[ \text{poor}_\text{medical} = \begin{cases} 1 & \text{if } \exp_h \geq \text{se}_h \text{ and } \exp_h - \text{OOP}_h < \text{se}_h \\ 0 & \text{otherwise} \end{cases} \]

Association between medical poverty and the number of children has been estimated using descriptive statistics and the Pearson chi-square test (Pallant, 2013). STATA 14 has been used for analysis.

Results

Incidence of medical poverty: all-India

Figure 1 below depicts percentage increase in the incidence of medical poverty compared to households with no child. The incidence of medical poverty increases only slightly in case of households with one or two children compared to households with no child. However, the incidence of medical poverty in households with three or more children increases by a substantial twenty-three per cent when compared to households with no child. This clearly suggests that in India, medical poverty is a concern for larger households with the need for government to protect households with three or more children.

The results of Pearson chi-square also suggest that there is a statistically significant association between number of children a household has, and if a household falls below the poverty line because of health expenses or not (chi-square=22.42, sig<0.01).

![Figure 1: Percentage increase in incidence of medical poverty compared to households with no child: all-India](source: Authors’ own)
The all-India results suggest medical poverty to five children and households with three or more children with medical poverty of households with two children (5.6 per cent), two children (5.1 per cent) and three or more children (5.9 per cent). The results in the case of urban India have been found to be completely unlike those of rural India. As shown in Figure 2, households with two children and households with three or more children, both have been found to have a high percentage increase in medical poverty compared to households with no child. Such result is expected as in an urban setting, raising a child is more expensive.

The Pearson chi-square test has also been found to be statistically significant at five per cent, suggesting a statistically significant association between number of children in a household in rural India and the household falling into medical poverty (chi-square=10.29, sig<0.05). This is primarily because of the difference in incidence of medical poverty of households with two children and households with three or more children.

As expected, quintile five households have been found to have virtually zero per cent incidence of medical poverty, irrespective of number of children in a household. This clearly suggests that raising more children is not a concern for wealthy households.

In the case of quintile one, though absolute incidence of medical poverty differs only by a small percentage points in the case of families with no child, one child, two children and three or more children, the percentage increase in incidence of medical poverty compared to households with no child has important implications. The incidence of medical poverty in the case of households with three or more children increases by fifteen per cent compared to households with no child. The incidence of medical poverty even increases by twenty-six per cent and eighteen per cent in the case of households with one child and two children compared to households with no child. This clearly suggests that for the poor, raising even one child makes them extremely vulnerable to falling below the poverty line.

The association between number of children and medical poverty seems to be valid only for low-income households and not rich. This association has also been supported by results of Pearson chi-square test which has been found to be statistically significant at ten per cent in case of household falling into medical poverty for quintile one (poorest twenty per cent) and quintile five (richest twenty per cent) households. Expenditure has been taken as an approximation of income to estimate quintiles, by following previous literature (Pal, 2012). The results are shown in Table 1.

### Table 1: Incidence of medical poverty in quintile one and quintile five households

<table>
<thead>
<tr>
<th>Quintile</th>
<th>Quintile 1</th>
<th>Quintile 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>No child</td>
<td>10.26</td>
<td>0.22</td>
</tr>
<tr>
<td>One child</td>
<td>12.96</td>
<td>0.36</td>
</tr>
<tr>
<td>Two children</td>
<td>12.09</td>
<td>0.02</td>
</tr>
<tr>
<td>Three or more children</td>
<td>11.8</td>
<td>0</td>
</tr>
</tbody>
</table>

Discussion

This study has attempted to understand the role played by the number of children in a household in making children resilient to poor health. This has been done by comparing the incidence of medical poverty in households with no child, one child, two children and three or more children.

Medical poverty has been found to be a big cause for concern in the case of households with three or more children in the case of India. Irrespective of the location of the household, rural or urban, households with three or more children have a higher incidence of medical poverty compared to households with no child. Children in the poorest twenty per cent households are the most vulnerable where even raising one child makes a household extremely vulnerable to falling below the poverty line.

Making children resilient to poor health would require extra support for larger households in India, especially for urban India. This support may come in the form of different health care schemes for larger households from the Indian government. The importance of government initiatives such as vaccination programmes, clean water and nutrition cannot also be emphasised enough in making children resilient to poor health in urban India.

Figure 2: Percentage increase in incidence of medical poverty compared to households with no child urban India

Source: Authors’ own
The slight difference in incidence of medical poverty as per different number of children in a household in rural India could be primarily because of two reasons (Brown, Hole, & Kilic, 2014; Somkotra & Lagrada, 2009). Firstly, people in rural areas, especially poor, prefer public health services over private ones, wherein the latter is much costlier, thereby reduction in medical expenses and hence less likelihood of falling in medical poverty. Secondly, many poor do not access health services because of concern for incurring health expenses. For this reason, such households are not falling into medical poverty but their condition is perhaps worse than those in medical poverty.

India is all set to achieve its millennium development goal of under-five mortality rate of forty-two per 1,000 live births (GOI, 2014b). However, the health of already born children in India is in a bad state. Only sixty-one per cent of children (two to twenty-three months) are fully immunised (GOI, 2014b), leaving them extremely vulnerable to fall sick and catch diseases at a later stage in their lives. This indeed increases health expenses of the household, making them vulnerable to falling below the poverty line.

The draft national health policy 2015 (GOI, 2014b) has laid out one of its objectives as to assure the universal availability of free, comprehensive primary health care services for all aspects of child and adolescent health and the most prevalent communicable and non-communicable diseases in the population. Such an objective is a welcome move for children in India. However, it would be only over the period of next few years that it will be realised how far the government has been successful in materialising its objective.

Given the poor quality of public health care services in India (Bali and Ramesh, 2015), achieving high quality universal health coverage is nearly impossible for India in the short-run. However, making different health policies for households with different number of children may indeed put India on a faster pace towards achieving the goal of healthy India.

References


Monte Carlo simulations, which is nearly impossible for India in the short-run. However, making different health policies for households with different number of children may indeed put India on a faster pace towards achieving the goal of healthy India.

References


Acknowledgements

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Dr Lee-Ann Burke is a lecturer in School of Economics, University College Cork. She was awarded a PhD from University College Cork in 2010. She previously graduated with a BA Joint Honours Degree in Economics and French and an MA in Economics from University College Cork. Her principal research interests are in the area of mental health. Areas investigated in her PhD were the determinants of mental health status and mental health related inequalities and dynamics over time through implementing panel data methods and factor analysis techniques.

Dr Edel Walsh is a lecturer in School of Economics, University College Cork. She previously graduated with a BA Joint Honours Degree in Economics and Sociology and an MA in Economics from University College Cork. Her principal research interests are in the area of subjective well-being. Edel is Director of the MSc Economics of Business Practice, which is a distinctive, practice-oriented postgraduate programme, through which participants can develop an applied knowledge and comprehensive understanding of how business operates.
The impact of early childhood on future health

Melissa Canny, Anna Clarke, Fionnuala Cooney, Julie Heslin, Phil Jennings, Caroline Mason Mohan, Áine McNamara and Ruth McDermott
Introduction

This research summary brings together the most recent research on the impact of early childhood on future health. It presents the evidence on the role that the health sector might have in providing cost-effective programmes and services for children and their families. It outlines five key actions that the Faculty of Public Health Medicine feels would strengthen the role of the health services in the lives of children. It advocates for additional and ring-fenced resources to support child health and wellbeing and calls for continued health service involvement in efforts across sectors to provide a multi-agency, co-ordinated response to support children and their families and communities.

The experiences that a child has in early childhood impact on the health of that child when he or she reaches adulthood.

Babies’ brains undergo rapid development before birth and in the early years of life (Centre on the Developing Child, 2009). Adverse experiences which occur in this critical developmental period impact negatively on the developing brain and on other sensitive organs. Such impacts may be seen in childhood but often manifest only in later adult years as chronic disease, such as cardiovascular disease, diabetes, obesity, mental health disorders (Centre on the Developing Child, 2010). The health and wellbeing of our current child population, therefore, determines the health of our future adult population.

There are a number of early childhood interventions aimed at child development, educational disadvantage and parenting which have been shown to be effective in improving child health and wellbeing, and thus later adult health and wellbeing. Investment in these programmes and services provides a greater rate of return than later interventions, with the most effective time to intervene being before birth and in early childhood (Heckman J and Masterov D, 2007; Wave Trust, 2013). These interventions can help to break the cycle of disadvantage and lay the foundation for addressing health inequalities (Marmot M, 2010).

The health and wellbeing of our children is not solely determined by what happens in the healthcare arena, but the health service has a unique and valued role in the provision of services for pregnant women, babies and the families of young children. These help to build the foundation for a healthy childhood environment and supportive parenting.

This paper can be found at: https://www.rcpi.ie/news/releases/faculty-of-public-health-medicine-calls-for-investment-in-early-childhood-health-services/

References


Wave Trust (2013) The economics of early years’ investment, Appendix 4 in Conception to age 2 – the age of opportunity report.

Author information

Drs Melissa Canny, Anna Clarke, Fionnuala Cooney, Julie Heslin, Phil Jennings, Caroline Mason Mohan and Aine McNamara are Consultants in Public Health Medicine in HSE Departments of Public Health and the National Immunisation Office and Dr Ruth McDermott is a Specialist Registrar on the RCPI Public Health Medicine Training programme. All have worked on the public health review of the child health screening and surveillance service. Dr Jennings is the national lead for this review and for the HSE input to the Nurture Infant Health and Wellbeing Programme.
Introduction

The importance of high quality data on the service use and needs of children and young people with an intellectual disability (ID) is vital for health service planning. The National Intellectual Disability Database (NIDD) was set up in 1995 for this purpose. A lot has changed since the first Irish Census of Mental Handicap (as it was referred to then) in 1974, not least a 46% increase in the number of individuals recorded as having a moderate, severe or profound intellectual disability (Doyle, Hourigan & Fanagan, 2017; Mulcahy, 1976). People with intellectual disabilities are living longer and enjoying full lives but the need for services and supports continues. Appropriate planning for transitional periods in life, such as going to or leaving school, need to be carefully considered as well as the provision of suitable supports for family caregivers who play a pivotal role in the lives and support of children and young people with an ID. This research summary describes the population profile, current service use and future service requirements of those registered on the NIDD in 2016 and who are aged less than eighteen years.

Profile of population

The 2016 NIDD report is based on 28,275 people of which 8,918 (31.5%) were aged less than eighteen years. There were significantly more males under eighteen years registered (5,977, 67.0%) than females (2,941 23.0%) and those in the ten to fourteen years age group represented the largest age group (3,090, 34.6%), see Table 1 below.

Table 2 shows the level of ID of those aged less than eighteen years. As one would expect, a high proportion (2,381, 26.7%) do not have a verified level of ID most likely due to their young age and that diagnosis has not yet been assigned.

Current service use

Almost all children and young people lived at home (8,837,99.1%). The remainder lived in group homes or other residential services (79, 0.9%). Of the 8,888 people in receipt of day services, 4,147 (46.7%) were in special schools, 2,179 (24.5%) in mainstream schools with the remainder receiving other day care services. Multidisciplinary supports were provided to 7355 (89.2%) of the under eighteen population on the NIDD with speech and language therapy, occupational therapy and ID related medical services reported most frequently.

Future requirements

The 2016 NIDD report identified 534 new services or supports that would be required in the period 2017-2021. These include 43 residential services (8.1% of the new services required), eight (1.5%) day services and 483 (90.4%) residential support or respite services. Of the 8,892 children and young people in receipt of services, 3,071 (34.5%) services require change, mainly in day services (2,691, 87.6%) as children transition within the education system.

Conclusion

The NIDD shows that children and young people with an intellectual disability are availing of a number of disability services. The 2016 findings highlight that additional new and enhanced services are required, with an overwhelming need for respite and residential support services. Day services that support the transition from child to adult services and between educational settings are also in demand. The 2016 NIDD annual report and the associated complete set of tables are available on the HRB website: http://www.hrb.ie/publications/disability. The data are important in planning for these services for the future.

References


Author information

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Sarah Hourigan is a Research Analyst in the Health Research Board (HRB) working on the National Physical and Sensory Disability Database (NPSDD), the National Intellectual Disability Database (NIDD) and also the National Drug Treatment Reporting System (NDTRS). Sarah holds a BSc in Applied Psychology and a MSc in Applied Psychology.

Table 1: Gender and age group, NIDD 2016

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4 years</td>
<td>568</td>
<td>9.5</td>
<td>343</td>
</tr>
<tr>
<td>5-9 years</td>
<td>1,994</td>
<td>33.4</td>
<td>925</td>
</tr>
<tr>
<td>10-14 years</td>
<td>2,096</td>
<td>35.1</td>
<td>994</td>
</tr>
<tr>
<td>15-17 years</td>
<td>1,319</td>
<td>22.1</td>
<td>679</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>5,977</td>
<td>67.0</td>
<td>2,941</td>
</tr>
</tbody>
</table>

Table 2: Level of intellectual disability, NIDD 2016

<table>
<thead>
<tr>
<th>Level</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not verified</td>
<td>2,381</td>
<td>26.7</td>
</tr>
<tr>
<td>Mild</td>
<td>2,941</td>
<td>33.0</td>
</tr>
<tr>
<td>Moderate</td>
<td>2,941</td>
<td>33.0</td>
</tr>
<tr>
<td>Severe</td>
<td>830</td>
<td>9.3</td>
</tr>
<tr>
<td>Profound</td>
<td>136</td>
<td>1.5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>8,918</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Health service use and needs of children and young people with disabilities in Ireland

Anne Doyle and Sarah Hourigan
Introduction

The National Physical and Sensory Disability Database (NPSDD) is a national health information system that captures the use of and need for specialist disability services. Increasingly, it is recognised that national health data that is high-quality and timely can assist with policy and service planning.

The NPSDD was established in 2002 and is managed by the Health Research Board (HRB) on behalf of the Department of Health (DoH). The Health Service Executive (HSE) and service providers are responsible for collection of the data. Data on the service use and requirements of people with neurological, physical, sensory and/or speech or language disabilities are published each year in the annual reports of the NPSDD.

Individuals are registered on the NPSDD if they have a persistent disability and are in receipt of, or require, a specialised health or personal social service, and/or a specialised hospital service related to their disability. Participation in the NPSDD is voluntary and as not every individual who has a disability is availing of or requiring services, the database cannot provide a definitive epidemiological statement on the number of people with a particular disability or diagnosis. For this reason and due to issues of coverage, there is an under representation of children with physical and sensory disabilities on the NPSDD.

2016 data

In December 2016, there were 21,763 people registered (with consent) as using or requiring disability support services and of those, 5,606 (25.8%) were under eighteen years of age.

Age group and gender

There were significantly more males (3,504, 62.5%) than females (2,102, 37.5%) in the under eighteen years age group registered (see Table 1 for gender and age group).

<table>
<thead>
<tr>
<th>Age group</th>
<th>Total</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4 years</td>
<td>234</td>
<td>4.2</td>
</tr>
<tr>
<td>5-12 years</td>
<td>2,835</td>
<td>50.6</td>
</tr>
<tr>
<td>13-17 years</td>
<td>2,537</td>
<td>45.3</td>
</tr>
<tr>
<td>Total</td>
<td>5,606</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Table 1: Age group and gender, NPSDD 2016

Type of disability

Table 2 shows the type of disability of those aged less than eighteen years on the NPSDD. Living accommodation/living arrangements

The majority of those registered aged under eighteen years lived in private accommodation (4,206, 75.0%) or rented accommodation (1,362, 24.9%), with less than five children residing in a full time residential setting. Almost all 5,519 (98.4%) lived with family members.

<table>
<thead>
<tr>
<th>Diagnostic category</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical disability</td>
<td>1,171</td>
</tr>
<tr>
<td>Neurological disability</td>
<td>1,099</td>
</tr>
<tr>
<td>Speech and language disability</td>
<td>1,006</td>
</tr>
<tr>
<td>Hearing loss/deafness</td>
<td>160</td>
</tr>
<tr>
<td>Visual disability</td>
<td>128</td>
</tr>
<tr>
<td>Total</td>
<td>5,606</td>
</tr>
</tbody>
</table>

Table 2: Type of disability, NPSDD 2016

Diagnostic category

The most commonly reported diagnostic categories were: communication (including speech and language disorders, dyspraxia) (1,919, 34.2%), followed by nervous system (including cerebral palsy, spina bifida and hydrocephalus) (1,495, 26.7%) and intellectual / developmental (448, 8.0%). Of those reporting a secondary diagnosis (2,427, 43.3%), the most commonly reported secondary diagnostic categories were communication (662, 15.4%), behavioural (290, 5.2%) and nervous system (230, 4.1%).

Primary carer

The majority of those aged under eighteen years reported having a primary carer (5,507, 98.2%). Of those, 99.7% (5,491) lived with their primary carer. Most primary carers were parents (5,404, 98.1%); with the remainder described as siblings, foster parents, other relatives or ‘other’. The majority of primary carers were aged between 19 and 49 years (5,341, 97.0%).

Service use and requirement

The 2016 annual report presents the current service use and future requirements of those under eighteen (and those aged eighteen years +) in tabular format.

In 2016, the most frequently used services by those under eighteen were physiotherapy, occupational therapy, speech and language therapy and summer camp respite.

Conclusion

Having reliable data available to plan services for children and young adults with disabilities is essential if they are to receive the most appropriate services and supports to enable them to lead fulfilling and rewarding lives. The NPSDD annual report presents this information in text and tabular format on the HRB website www.hrb.ie/publications/disability. Further analyses of the data are frequently requested by the DoH, the HSE and in order to inform research relating to the provision of services for children and young people. Routinely reported data on specialist disability services plays an important role in policy making and service planning for the disability sector.

References


Author information

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Accommodating interruptions
A classic grounded theory explaining the behaviours of young people who have Asthma

Mary Hughes, Eileen Savage and Tom Andrews
Background

Accommodating Interruptions is a theory that emerged in the context of young people who have asthma, explaining how they address their main concern of participating in their chosen activities and social groups despite the restriction of having asthma (Hughes 2014, Hughes et al. 2017). Ireland has the fourth highest incidence of asthma in the world, with almost one in five Irish young people having asthma (Kabir et al. 2011, Manning et al. 2007). Although national and international asthma management guidelines exist, it is accepted that the symptom control of asthma in this population group is poor (Chang 2012, GINA 2012). Several factors are known to influence the control young people have over their symptoms, in relation to compliance, exposure to triggers and lack of individualised asthma plans (Ducharme et al. 2011, Schreier & Chen 2008).

Aim

The aim of this research was to develop a theory on the behaviours of young people (aged 11-16) who have asthma in relation to the impact of asthma on their lives, and the issues affecting them.

Methodology

This research was undertaken using a Classic Grounded Theory approach (Glaser & Strauss 1967). Using a systematic approach, patterns of behaviour identified in the data explain how young people maximize their participation and inclusion in activities, events and relationships in spite of their asthma. The core category of accommodating interruptions explains how they do this, by simultaneously assimilating behaviours in balance finding, moderating influence, fitting in and assuming control, the sub-core categories explained in the theory. These patterns of behaviour are explained providing a new way of understanding the lives of young people who have asthma.

Results

The theory explains the patterns of behaviour in how young people maximize their participation and inclusion in activities, events and relationships in spite of their asthma. The core category of accommodating interruptions explains how they do this, by simultaneously assimilating behaviours in balance finding, moderating influence, fitting in and assuming control, the sub-core categories explained in the theory. These patterns of behaviour are explained providing a new way of understanding the lives of young people who have asthma.

Conclusion

The theory of accommodating interruptions explains how and why young people behave the way they do in order to minimise the effect of asthma on their lives. The theory adds to the body of knowledge on young people with asthma and challenges some viewpoints regarding their behaviours. The theory may assist in design of services for young people that are meaningful for them, and relevant to them.

References


Eileen is Head of School, and Professor of Nursing in the School of Nursing and Midwifery, University College Cork. Her research interest is primarily on chronic illness management with a special interest in children and adolescents. She leads a programme of research within the School of Nursing & Midwifery titled Chronic Illness Management in Children, Adolescents & Adults. Specific areas of interest within this programme are: self-and family management, self-monitoring, symptom experiences and management, palliative care and quality of life experiences.

Tom is a Lecturer in the School of Nursing ad Midwifery, University College Cork. His methodological interest is in Classic Grounded Theory; he trained and studied under the direction of Dr Barney Glaser, one of the originators of the methodology and is considered to be a renowned expert in the methodology. His research interests are in all aspects of critical care, particularly in relation to the early detection of physiological deterioration and clinical decision making. His current research interest is in end-of-life care in Intensive Care.

Author information

Mary is an Assistant Professor and researcher in the School of Nursing, Midwifery and Health Systems in U.C.D., where she is Head of Subject (Children’s Nursing), and Director of the Children’s and General BSc Nursing. She is an active researcher with a special interest in Health and Wellbeing in Chronic Illness; adolescent health, asthma and chronic childhood illness in particular. Her publications to date are in peer review journals, professional journals, book chapters, by conference presentations, seminar contributions and conference abstracts.
Responding to the health needs of complex youth
Professionals’ perspectives

Tracey Monson
Introduction
This paper will present a brief overview of doctoral research being carried out with the aim of exploring how professionals from a range of different disciplines understand and categorise complex youth and the concepts of ‘risk’ and ‘need’. Objectives of the study are to understand the factors and discourses that influence assessments, judgements and decisions of professionals and their impact on service provision.

Characteristics and definitions of complex youth
The terms ‘complex youth’ and ‘dually involved’ youth (Huan, Ryan and Herz, 2011) or ‘cross over’ youth (Haight, Bidwell, Marshall, Khatiwoda, 2014) are used to describe a specific cohort of young people who are engaged in youth justice and child protection and welfare services. They are also more likely to be involved with other services relating to mental health, educational support and other support services (Biehal, Sinclair and Wade, 2014; Haight et al., 2014). Irish national policy, Better Outcomes Brighter Futures (BOBF) (2014) defines a group of young people that are at greater disadvantage than the general population of young people and are identified as experiencing greater challenges due to their involvement in a range of different services, including child protection and youth justice services. Implications for mental and emotional health are also significant, with the suicide rate among young people in Ireland, being the fourth highest in the EU within the 15-19 year age range (DCYA, 2014).

Methodology
The study was qualitative and adopted a social constructionism standpoint. The data were collected through semi-structured interviews and vignettes. Data were collected from 27 professionals from across six services that engage with complex youth; addiction, child protection and welfare, youth justice, mental health, education welfare and community/voluntary. The data analysis is ongoing and is using thematic analysis driven by a grounded theory approach. Themes within preliminary findings are presented.

Findings and discussion
The provisional findings suggest that a wide range of factors influence how professionals understand, assess and provide services to complex youth, and how risk and need are complex issues influencing these understandings. A significant factor is the challenge that professionals face in multi-agency responses stemming from the diversity of professionals and services engaging with complex youth. Findings suggest that the application of differing assessment models, thresholds of risk and need, and the availability of suitable referral pathways result in these vulnerable young people being met with a patchy and disparate service.

Conclusion
The findings of the study suggest that complexity of needs, involvement in multiple services, and differing assessment models present challenges for professionals across services in the assessments, judgements, decisions and service provision for complex youth. Moving towards a commissioning environment in which organisations have to prove the effectiveness of their services, based on outcomes, efficiency and value for money, there is a concern that the most vulnerable young people in society will continue to fall through the gaps while services struggle to balance demands of the organisation and funders, while providing a service for complex youth. The challenge for services will be to continue to work together to provide services that are balanced in responding to the individual needs, while demonstrating effective outcomes, to ensure sustainability of services for this vulnerable group. This is a challenge that faces those of us working in the sector, moving into the new unchartered era of service provision.

References


Author information
Tracey Monson, has worked with at risk children and families for over 16 years. She is Senior Manager with the Daughters of Charity Child and Family Service. She was formerly a Regional Manager for the North East Region with the ISPCC. Tracey holds a MA in Psychoanalysis (Clinical Specialization) a MSC in Equality Studies and is due to submit her Doctoral Thesis Professionals Perspectives of Complex Youth in the Republic Ireland in the autumn 2017. She is an editorial board member of the Journal of Childcare in Practice, since 2006 and a member of the Irish Criminology Research Network.
Children’s Research Network for Ireland and Northern Ireland

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