

The Reflux Roller Coaster: Dismissal, Delay and the Cost to Families and the Health System

A report by the Reflux Infants Support Association



www.reflux.org.au

ABOUT

Reflux Infants Support Association (RISA)

The Reflux Infants Support Association (RISA) Inc. is a not-for-profit community organisation that provides support to families of infants and children who suffer from gastro-oesophageal reflux and its complications. It is run by reflux families for the benefit of reflux families, and has done so since 1982. RISA offers a wide and varied range of services to support families who have babies or children who suffer from gastro-oesophageal reflux.

Website: www.reflux.org.au

ACKNOWLEDGMENTS

RISA would like to thank all the parents who took the time to complete the survey and generously shared their stories, experiences and ideas with us in the hope that by doing so, we can raise awareness of gastro-oesophageal reflux and improve how our health system responds.

RISA also thanks and acknowledges:

- RISA Executive and Advocacy Committee members who contributed to this project: Joanne Matthews, Sarah Barter, Chin Yin Chim Henschke, Gabi Simpson, Trina Coulson, Maddy Black, Plum Stone, Carla Cram, Corin Miller, Belinda Causby, Kathy Williams
- Allison Salmon who independently analysed the qualitative survey data.
- Dr Jonny Taitz and Dr Michaela Baulderstone who provided feedback on the draft report.

Foreword

In June 2016, the Reflux Infants Support Association Inc (RISA) conducted a survey into the experiences of parents caring for a baby with gastro-oesophageal reflux disease (GORD) in the first year of life. The survey was prompted by anecdotal evidence of delays in diagnosis, inconsistent management and extreme fatigue and distress experienced by families of children diagnosed with GORD. We were concerned by the apparent increase in number of babies being diagnosed, the inconsistency of their treatment plans and the extreme distress of particularly mothers with children diagnosed with this condition. The survey also explored the timing and nature of diagnosis and treatment options, the impact that these babies have on parents' physical and mental health, relationships and finances.

The RISA Executive team were concerned by what appears to be the extended and unnecessary suffering of babies and their families; and, not insignificantly, the unnecessary cost to the health system of a poorly understood condition. We are particularly concerned by the evidence of parents being put in a position where they take risks with their own and their child's safety in lieu of viable treatment and management options. The risk of harm to babies and mothers in this population is significantly higher than the average population and it warrants attention for that reason alone.

By sharing these stories, we hope to raise awareness of the medical condition, its complications and the impact of caring for babies with GORD on parents and the families. We also hope to acknowledge the concerns of families and reduce an underestimated burden on the health system. We believe that a modest investment in research and education about infant GORD could yield enormous benefits for all. As with most paediatric conditions there is evidence to suggest that early intervention could be of enormous benefit.

As a mother of two children diagnosed with this condition it is my devout wish that no child ever has to suffer what my children have suffered and that no parents ever have to live the life we lived to get to the point of having well children. Most of the contributors to this report have voluntarily provided their professional skill with the same outcome in mind. No one should go through what our children have gone through. And there is far more we can do.

We just don't know the extent of the problem as it's not been investigated in Australia. We need to know how many babies are being prescribed acid suppressing medication in the first year of life in order to understand the incidence of the disease. We need to know what proportion of allied health services are being taken up by children with GORD. We need to know what proportion of paediatric, gastro paediatric and paediatric allergist services are being taken up with GORD cases. We need to know why less complex cases are being managed by specialists and more complex cases are not being expedited. We need to know what proportion with this eventual diagnosis are simply at the GP multiple times a week for lack of effective management options. We need to know what proportion of parents are actually being diagnosed and treated for post-natal depression (survey says 32% but with a further 24% identifying themselves as

suffering undiagnosed depression or anxiety). And we need to have some idea of how much of this is atopic reaction of an internal nature. There are indications that this is almost as big a problem and cost to the system as childhood asthma and that a proportion of childhood respiratory disease is in fact a symptom of gastrointestinal disease.

It is vital that parents of infants with GORD have timely access to family-centered health care and the necessary psychosocial supports to enable them to care for themselves, their child and rest of the family.

This is a bigger problem than the system currently realises and the stories in this report are genuinely shocking at times. But there are low hanging fruit to be picked and big yields to be harvested that will alleviate a huge amount of suffering and save the system enormously with a better coordinated, better researched approach to the condition.

I can only thank all the wonderful contributors to this report and in particular Sarah Barter and Chin Yin Chim Henschke. The need has existed for a long time and the report would not have been written without their enormous effort and multitude of talents.

I commend it to your reading and would be thrilled to provide any further information on the numbers provided below. RISA would be grateful for the opportunity to provide cooperation to any authorities or other stakeholders interested in the worrying findings of this report.

Gratefully,

Joanne Matthews
National President
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CMPI/A	Cow's milk protein intolerance/ allergy
GOR	Uncomplicated gastro-oesophageal reflux; this occurs when the gastric contents pass from the stomach into the oesophagus.
GORD	Gastro-oesophageal reflux disease; this occurs when the reflux of gastric contents leads to "troublesome symptoms and/or complications" ²
GP	General Practitioner
Health practitioner	Health practitioner is used as an inclusive term to describe anyone with responsibility for reviewing and assessing health needs including nurses, pharmacists, medical practitioners and allied health practitioners.
Parent	Parent is used as an inclusive term to describe anyone with primary responsibility for caring for an infant with reflux. This may include carers and guardians. For this survey, all respondents identified as a parent.
RISA	The Reflux Infants Support Association

Executive Summary

In 2016, the Reflux Infants Support Association (RISA) surveyed its members and other parents about their experiences caring for an infant with gastro-oesophageal reflux disease (GORD), concentrating on the first 12 months of life. More than 500 parents in Australia responded to the survey over a two-week period. The results of the survey provide vital information about the experience of parents and the outcomes of infants experiencing reflux, which can be used to improve health care and the diagnosis and treatment of GORD. This is the first Australian study that explores the impact of GORD on the child, parent and families at this scale.

Infants with GORD often present with a range of symptoms that occur across the spectrum from mild to severe. This can make it difficult for health practitioners to reliably diagnose GORD from less complicated gastro-oesophageal reflux (GOR), or even normal infant behaviour. In this survey, many respondents felt that their concerns were not taken seriously by health practitioners, which delayed diagnosis and access to appropriate treatment and management. Over 40% of respondents felt that the health practitioners involved in their child's care did not have a good understanding of infant GORD and its complications and did not adequately support them in caring for their child. The importance of health practitioners taking the time to listen to parents and their concerns has been highlighted by the advocacy of the Day family following their son's, Kyran, death as a result of misdiagnosis.¹

Many children with GORD often have a range of co-occurring conditions and complications including gastrointestinal, respiratory, ear nose throat, dermatological conditions and/or developmental delay which require close management by a team of health practitioners. It is essential that these conditions are identified early so that care can be coordinated in an interdisciplinary manner with parents as a key partner. Unaddressed, a child with GORD and its complications may go on to have a range of chronic conditions that require ongoing management, health service utilisation and hospital admission. These conditions can impact the ability of the child to participate in school and other activities, potentially affecting their educational attainment.

The impact of GORD on infants, parents and families is enormous. Caring for an infant with GORD takes a huge toll on parents and families particularly on their physical and mental health and relationships. The impact is worsened by the time and cost involved in navigating a health care system which frequently dismisses parents' concerns leading to delayed diagnosis and treatment and disproportionate use of health services. The survey results depict multiple adverse effects on children experiencing GORD and their parents. Prolonged sleep deprivation, stress, anxiety and frustration can negatively affect the bond between parent and child and place both at risk of physical and mental harm.

“There is an ongoing level of guilt and sadness and anxiety. While I am so thankful for those very few medical practitioners who took us seriously, I am so sad that it took so long and caused so much unnecessary pain.”

¹ ABC News, 'Kyran Day death: Six-month-old died after 'cause of illness undetected' by medical staff at Shoalhaven Hospital' (21 December 2016), <http://www.abc.net.au/news/2016-12-21/kyran-day-inquest-finds-misdiagnosis-inadequate-fluid-treatment/8137762>.

Recommendations

1. Collect and analyse data in relation to the incidence and treatment of infant GORD and its complications to better understand and quantify the cost to the child, family and health system.
2. Provide information brochures on GORD and its complications in hospitals, the child health record booklet, pharmacies, general practices and community health centres.
3. Develop education and training modules for health services, health practitioners and parent and family support services to enable early recognition of the signs and symptoms of GORD, referral to appropriate health and psychosocial support services, and the provision of more holistic, family-centred health care.
4. Establish an expert committee with parental input to develop clinical guidelines. The guidelines should identify 'red flags', encourage empathy, listening and support for parent concerns, and recommend health practitioners take the time to thoroughly assess the infant to enable timely diagnosis and treatment of GORD.
5. Review utilisation of the Pharmaceutical Benefits Scheme (PBS) to enable timely and appropriate access to subsidised medications, particularly compounded omeprazole (Losec), and specialty formulas for infants with GORD and its complications. GPs and paediatricians should be supported to prescribe when red flags are present or in accordance with clinical guidelines.
6. Increase awareness of GORD as a 'gateway' condition to a range of other conditions including allergies, gastrointestinal, immunological, respiratory, dermatological, ear nose throat and developmental. Improve monitoring and recall of infants with GORD to enable early intervention and follow-up.
7. Invest and commit to new research and funding into diagnostic and therapeutic approaches for infants with GORD, the risk of co-occurring conditions, and the longitudinal biopsychosocial impact of GORD on children and families.
8. Enable parents to request a home visit from a child and family health nurse when the child's condition makes it difficult for them to leave the house.
9. Provide coordinated interdisciplinary team care for infants with complicated GORD. Parents should be considered core members of the interdisciplinary team. Team care and communication can be facilitated by the creation and implementation of a shared care management plan for infants with GORD. The care plan should be owned by parents, utilised by health practitioners and provided to services involved in the child's care (e.g. child care centres).
10. Train care coordinators who can provide easily accessible advice and support parents to manage the complex health care needs of babies with GORD and its complications. This advice can be provided online or by phone and potentially face-to-face where the circumstances warrant it.

Introduction

Gastro-oesophageal reflux (GOR) occurs when the gastric contents pass from the stomach into the oesophagus. This occurs in up to 50% of healthy newborn babies born at term.² In this age group it is a physiological process and in 95% of cases it resolves spontaneously by 12-18 months of age.³ Gastro-oesophageal reflux disease (GORD) occurs when the reflux of gastric contents leads to "troublesome symptoms and/or complications".² Complications of GORD include failure to thrive (where the infant has insufficient weight gain), frequent large volume regurgitation, feed refusal, respiratory symptoms, haematemesis, oesophageal stricture and oesophagitis.⁴

There is currently no simple and reliable test to diagnose an infant with GOR or GORD. As a result, it is difficult to estimate the true incidence of this condition, however it is said to affect up to 5% of infants.⁵ GORD may also be a presenting symptom of food allergy or other pathology, with between 16-42% of infants with GORD also showing signs of cow's milk protein allergy.⁶ The treatment and management of GORD relies on the ability of the clinician to distinguish between GOR and GORD and identify CMPA. Infants with GORD and CMPA require further assessment, treatment and management whereas conservative management only is recommended for infants with uncomplicated reflux.⁷

Treatment decisions for GORD in infants can be equally as challenging as the diagnosis of the disease. Increased use of acid suppressant medication such as Histamine₂ (H₂) antagonists and proton pump inhibitors (PPI) has been noted in the literature. In the USA, for example, from 1999 to 2004, there was a sevenfold increase in the use of prescription medications to treat GORD in infants younger than 1 year.⁸ This increase is despite the limited number of Randomised Controlled Trials (RCTs) demonstrating their safety and efficacy in treating infant GORD. A Cochrane Review found some moderate quality evidence to support the use of PPIs and H₂ antagonists but further research and trials are needed.⁹

² Vandenplas Y, Rudolph CD, Di Lorenzo C et al. North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN), and the European Society for Pediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN). (2009). 'Pediatric Gastroesophageal Reflux Clinical Practice Guidelines'. *Journal of Pediatric Gastroenterology and Nutrition*.

³ Kirby CN, Segal AY, Hinds R, Jones KM and Piterman L. (2015). 'Infant gastro-oesophageal reflux disease (GORD): Australian GP attitudes and practices'. *Journal of Paediatrics and Child Health*. doi:10.1111/jpc.12983.

⁴ Allen K, Ho SS. (2012). 'Gastro-oesophageal reflux in children--what's the worry?'. *Aust Fam Physician*. 41(5):268-72.

⁵ Silva D, Mews C. (2007). 'How to Treat. The Unsettled Infant'. *Australian Doctor*. <http://www.australiandoctor.com.au/cmspages/getfile.aspx?guid=df5adece-3051-4eb9-99c1-2f1917604125>.

⁶ Vandenplas Y, Brueton M, Dupont C, Hill D, Isolauri E, Koletzko S, Oranje A & Staiano A. (2007). 'Guidelines for the diagnosis and management of cow's milk protein allergy in infants'. *Archives of Disease in Childhood*. doi: 10.1136/adc.2006.110999.

⁷ Lightdale JR, Gremse, DA. (2013). 'Gastroesophageal reflux: management guidance for the pediatrician'. *Pediatrics*. doi: 10.1542/peds.2013-0421.

⁸ Scherer LD, Zikmund-Fisher BJ, Fagerlin A & Tarini BA. (2013). 'Influence of "GERD" Label on Parents' Decision to Medicate Infants'. *Pediatrics* 131(5).

⁹ Tighe M, Afzal NA, Bevan A, Hayen A, Munro A & Beattie RM. (2014). 'Pharmacological treatment of children with gastro-oesophageal reflux'. *Cochrane Database Systematic Reviews*. DOI: 10.1002/14651858.CD008550.pub2.

In Australia, there are a range of guidelines and information designed to help GPs and hospital clinicians treat and manage GORD in infants.¹⁰ These guidelines generally state that GOR is common and GORD is rare, crying is normal, parents should be reassured and conservative treatment and management is recommended. Despite the availability of these guidelines, a recent paper found that ‘high-level evidence-based guidelines for GPs are lacking,’ and GPs have concerns about the safety and effectiveness of diagnostic and management practices.³ More sensitive and specific clinical information and guidelines about GORD in infants is required to improve quality of care, the child’s quality of life, achieve better health outcomes, and reduce overall health costs.

Case for Change

There are a significant number of infants in Australia diagnosed and treated for GORD annually. It is difficult to estimate the prevalence and incidence as there is a paucity of research and data publicly available. The information and evidence available to support health practitioners and health services in Australia to diagnose, treat and manage GORD and its complications in infants is also limited. As a result, the health care journey for infants with this condition is likely to be long and difficult resulting in increased pressure being placed on a stretched health care system and detrimental effects on the child’s and the parents’ health and quality of life.

Case study¹¹

Charlotte is 6 weeks old and lives with her mother in regional NSW. Charlotte is very unsettled and irritable and has a history of voluminous posseting, loose stools, eczema and nasal congestion. Her mother reports these symptoms to the child and family health nurse at her next check-up and is advised that ‘all babies cry’ and the symptoms are normal. She is not provided with any further information nor referred to other medical or psychosocial services. Two weeks later, Charlotte’s mother presents to the local hospital Emergency Department with Charlotte. They are both very distressed. The doctor assesses Charlotte but, because she is putting on weight, discharges her without further treatment or management. Over the course of the next few months, Charlotte continues to present to GPs and hospital with a range of complications including constipation, recurrent otitis media and bronchiolitis. Eventually, Charlotte is referred to a paediatrician for further assessment. This paediatrician is experienced in GORD and diagnoses Charlotte with GORD and cows’ milk protein intolerance. The paediatrician prescribes a proton pump inhibitor, non-cow’s milk formula, laxatives and refers Charlotte for blood tests and to an allergist and an ear nose throat specialist. The cost and time Charlotte’s mum spends attending these appointments and managing Charlotte’s treatment is incredibly stressful and means she cannot return to work as planned. Charlotte’s mum is diagnosed with post-natal depression and anxiety. Charlotte’s mum feels that the stress has negatively impacted on her relationship with her child and she is unwilling to have any more children in future as a result of her experience.

¹⁰ The Royal Children’s Hospital Melbourne, Gastroesophageal reflux in infants, http://www.rch.org.au/clinicalguide/guideline_index/gastroesophageal_reflux_in_infants/; NPS (2013), Help parents cope with infant GORD without PPIs, <http://www.nps.org.au/publications/health-professional/health-news-evidence/2013/infant-gord-ppis>; NSW Health. (2016). Infants and Children: Acute Management of the Unsettled and Crying Infant. 1st Edition. Clinical Practice Guideline GL2016_010.

¹¹ This case study is fictional but represents the stories shared by survey respondents and RISA members.

Methods

In 2016, a small Working Group of RISA members developed an online survey of 57 questions, including six open-ended questions, using Survey Monkey. The survey questions explored parents’ experiences accessing health care to diagnose, treat and manage GORD and its complications in the infant’s first year of life, as well as the impact caring for the child’s condition had on the child, parent and family.

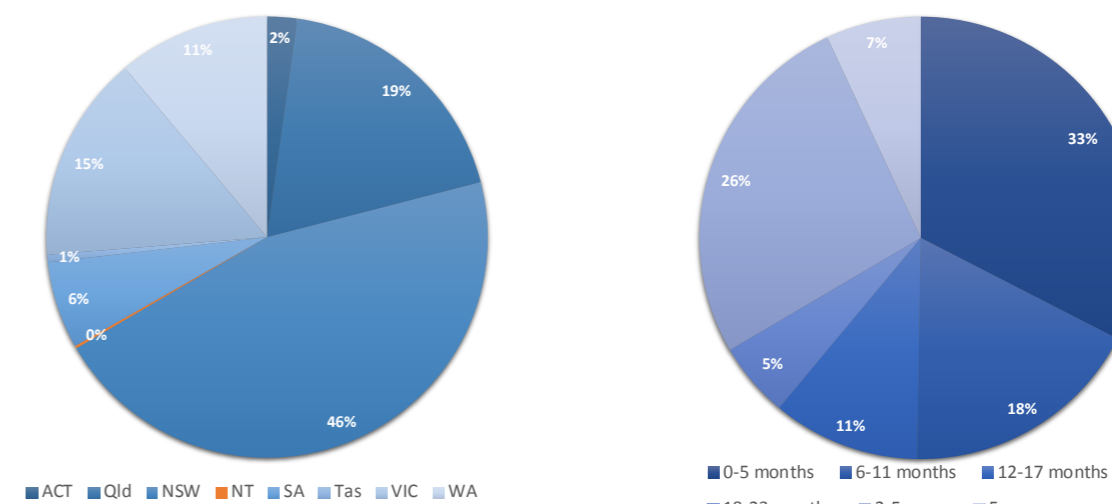
A link to the survey was distributed to RISA members through the Facebook group (n= 460 private members and 9,500 public followers) and was also promoted via relevant Australian-based online communities for parents including Facebook Mum’s Groups and the BabyCenter forums.

The quantitative data was analysed using the Survey Monkey software and Microsoft Excel. The qualitative data was analysed using specialist software (N-VIVO 11) to identify major themes and any relevant sub-themes. Qualitative analysis was undertaken by an independent consultant engaged by RISA and funded through crowd-funding. Findings from the analysis were reviewed, and logic tested, by members of the RISA Executive Committee. The recommendations were formulated by the RISA Executive from the survey results and analysis.

Results

The survey received 547 responses (excluding incomplete responses and respondents living outside Australia) over a two-week period in July 2016.

Most respondents (95%) identified as the female parent of the infant with GORD and were aged between 30-39 years (66%). The majority of respondents were married (54%) and lived in NSW (46%) followed by Queensland (19%), Victoria (15%) and Western Australia (11%). Thirty-three percent of respondents were in paid full-time or part-time employment while 23% identified as a stay-at-home-parent. Half of all respondents were caring for an infant aged less than twelve months (0-5 months, 33%; 6-11 months, 18%).



(a) Location of survey respondents

(b) Age of child with GORD

a. Towards a diagnosis

There is currently no validated tool to diagnose GORD in infants in Australia. Diagnosis relies on the clinical judgement of the health practitioner based on the history, observation and assessment of the child. In Australia, a General Practitioner (GP) or paediatrician would be the health practitioner that most commonly diagnoses infants with GORD. However, the pathway by which parents reported obtaining a diagnosis of GORD for infants was highly variable. A number of respondents reported that they specifically sought out a diagnosis of GORD from a GP or paediatrician after suspecting the condition themselves or having the condition suggested by a family member, friend or other support person such as a midwife, community/Mother Craft nurse or lactation consultant. A strong relationship with an informed and empathetic GP was often key to a timely diagnosis and positive experience of the health system, as reflected in the following quote:

“...Finally, I came across a wonderful GP who as soon as he saw my son said, “oh I see your son had silent reflux.” Changed our lives. I cried the whole way home. 8 months of pain for my poor baby.”

A challenge for health practitioners in diagnosing GORD is that many of the presenting signs and symptoms lie on the spectrum of normal baby development and behaviour. What often distinguishes a baby with GORD from other babies is the multitude and the severity of symptoms. Unfortunately, in practice this means that diagnosis is often delayed and symptoms dismissed by health practitioners, community supports and family and friends as ‘normal baby noises’, ‘colic’, ‘happy chucking’ or a result of a milk under- or over-supply. The dismissal of symptoms often continues until there are clear red flags such as bleeding or failure to thrive.

“We were unable to get any help until a bleeding oesophageal ulcer. [We were] at the doctors every single week. Twice the day before the bleed occurred, every time told nothing is wrong.”

In this survey, just under half of all respondents (42%) reported noticing symptoms when the infant was less than 2 weeks old although most didn’t receive a formal diagnosis until between 6 and 12 weeks (37%). A further 20% were diagnosed between 3 and 6 months old. The most common initial presenting symptoms reported were frequent hiccups (72%), silent reflux (62%), overt regurgitation (55%), bloated stomach (30%) and congested nose (30%). Other signs included severe unsettledness and irritability, back-arching and distress while feeding, and a preference for being held upright. For infants also diagnosed with cow’s milk protein allergy/intolerance (CMPA/I) or multiple food protein intolerances (MFPI), 47% also reported blood or mucus in the stool.

Many respondents reported significant dissatisfaction and distress with the process of obtaining a formal diagnosis. A strong theme was the experience of being dismissed as an “over-anxious first time mum” when parents presented to health practitioners with children experiencing symptoms and signs of reflux.

“I fought so hard and feel immensely let down by all medical practitioners. I was persistently turned away as a ‘new young mother’ and told ‘babies cry’. Every appointment, every hospital trip I was made to feel small and crazy.”

Symptoms were also routinely dismissed when they co-occurred with a baby gaining weight; that is, if a baby was gaining weight then health provider was reluctant to provide treatment. It often took multiple visits to many health practitioners for parent’s concerns to be acknowledged and a diagnosis made. The outcome of this was often a delay in a referral, diagnosis, treatment and, ultimately, relief for the child and family. As stated by respondents:

“It took 3 GP’s, 5 community nurses and a finally a lactation/gp consultation before anyone would listen to me!”

“It has been nearly impossible to obtain support and or a diagnosis. I have spent thousands of dollars and countless hours travelling in a bid to get answers. 11 months – nothing...”

Many parents felt they had to strongly advocate for their child and ‘push’ for a referral from a GP to a specialist. Video evidence was often reported as necessary to be ‘taken seriously’. One respondent noted that:

“It was incredibly difficult to get a clear diagnosis and we needed to do a lot of the research ourselves eventually demanding tests, referrals and prescriptions ourselves.”

The continual dismissal of parental concerns by health practitioners can undermine parents’ confidence and negatively affect their mental health, as reflected in the following quote:

“It was horrible as a new mum to be fobbed off by so many different health practitioners, the self-doubt crept in and I also ended up with Post Natal Depression and Anxiety.”

It can also make bonding with the baby difficult and lead to behavioural challenges with older siblings.

“Reflux; it ruined the initial bonding time I had with my child. It took away the special newborn baby love.”

“[We had a] 2 year old sibling whose behaviour dramatically deteriorated as this new [baby] took ALL of both our attention and care... her behaviour was far worse than sibling rivalry and she had every reason to act out. His crying was relentless.”

Respondents from rural and regional Australia experienced even greater difficulty obtaining a diagnosis of GORD due to the distance to health care. Additionally, respondents were concerned about the lack of knowledge of GORD among local rural and remote medical staff. For example:

“The diagnosis was not acted upon because of remote location - no access to paediatrician for first 3 months and then very ad hoc care after that - with a 12 month wait for review”

“The lack of medical support networks in the country (R.I.S.A. is amazing) is frustrating. Our local medical staff have very very limited knowledge of Silent reflux and management plans.”

The ability to access an earlier diagnosis for second and subsequent children was a strong theme when parents reflected on their experiences with multiple children with GORD. A parents’ ability to advocate for subsequent children and their increased assertiveness with health

¹² Asthma is rarely diagnosed in children under 12 months of age so this figure is likely to be for parents caring for a child older than 12 months.

practitioners was reported as key to earlier recognition, diagnosis and treatment leading to more consistent and coordinated care.

“[I] pushed earlier and harder for tests and intervention for 2nd child. [I] understood more and did not let Doctors blow it off as ‘just reflux’ they will outgrow it”

In addition to being diagnosed with GORD, many respondents reported additional diagnoses for their children including CMPI (33%), MFPI (17%), asthma (7%)¹², otitis media (4%), Sensory Processing Disorder (6%) and Autism Spectrum Disorder (2%). Given that the majority of respondents were caring for infants less than 12 months old, and many of these additional diagnoses are not made until later in childhood, we can expect that these proportions are under-estimates and will increase over time. On this basis, GORD may be considered a ‘gateway’ disease. Infants with GORD should be monitored to ensure early diagnosis and intervention for these debilitating conditions, which increase health service utilisation and impact the child’s quality of life and educational attainment.

b. Initial treatment

There is no single, endorsed clinical guideline in Australia for infants with GORD. In addition, there is dearth of evidence regarding effective treatment of GORD and its complication in infants in the first year of life. Of the guidelines and information that does exist, most are short and prioritise conservative treatment and reassurance of parents except in the most severe cases. The result is that doctors may be reluctant to medicate babies and the starting treatment dose for anti-reflux medications is widely variable. Many infants need a rapid and regular increase in dosage to effectively manage GORD. For example, respondents reported that:

“Regular need for dosage changes due to weight gain were not always occurring in a timely manner which led to regular periods of severe symptoms.”

Respondents noted the effect that the emphasis on conservative treatment by many health practitioners had on the parent. One parent said that:

“Still today, doctors tell me I am medicating him for no reason (still on moderate dose PPI). There is an ongoing level of guilt and sadness and anxiety.”

In this survey, the most commonly prescribed medications for infants with GORD were PPIs, which nearly 80% of respondents reported using, and H2 antagonists, which nearly 50% of respondents reported using. Medication was frequently reported to be successful with respondents noting significant improvement in symptoms following initiation and establishment of anti-reflux medication.

Aside from anti-reflux medications, parents also reported using other treatments to manage the symptoms and complications of GORD including using antacids, stool softeners for constipation, thickener, probiotics and attempting an elimination diet or using non-cow’s milk formula for babies with suspected or diagnosed CMPI/A or MFPI/A. Other procedures, such as endoscopy (14%) or fundoplication (3%), were reported by a small number of parents caring for an infant with severe GORD. Some infants may also develop a severe feeding aversion as a result of GORD and require enteral tube feeding to ensure sufficient nutrient intake and weight gain.

However, many respondents felt that insufficient support was provided by health practitioners following diagnosis and initial treatment of GORD. More than 40% of respondents felt that the health practitioners involved in their child’s care did not have a good understanding of infant GORD and its complications and did not adequately support them in caring for their child. Only 6% of respondents reported having a key health practitioner involved in coordinating the child’s treatment and management. Many felt cast adrift and isolated with little advice provided about how to manage the day-to-day of the condition including limited sleep and ongoing unsettledness of the baby. Parents received few referrals for psychosocial support and ongoing care or follow-up was often inadequate. Parents noted:

“Shocking level of understanding but also empathy. I dare them to go one night in our house - they wouldn’t be able to.”

“As first time parents, neither the GP or pediatrician really acknowledged or explained how stressful or the severity of what we had and would experience. Neither suggested support groups such as yourselves or any other resources, we were just eventually given a diagnosis and a script and sent on our way.”

“Osteopath helped a lot as well as chiropractor... still has reflux but that pain seems to have subsided”.

These treatments and therapies are not evidence-based and may cause harm to the infant. However, the demand demonstrates the need for treatment and the lengths parents will go to in an effort to obtain some symptom relief for their child. It also highlights the value of having a trusted medical or health professional available to help parents navigate the myriad of available treatment and therapy options.

c. Managing at home

Beyond medical and alternative treatments, many parents reported using other techniques to minimise and manage the child’s reflux. Some of these are commonly recommended by health practitioners including keeping baby upright after feeds; offering smaller, more frequent feeds; and using a dummy. Of more concern was the sleeping practices of the majority of respondents who, in direct contrast to safe sleeping advice, resorted to an array of unsafe sleep practices including sleeping baby upright including in arms, carrier or bouncer (74%); and elevating the cot (87%). Fifty percent (50%) of respondents introduced solids earlier than the recommended 6 months on advice of a health practitioner. However, only 13% of these respondents reported that the introduction of solids reduced reflux symptoms. Furthermore, certain foods, such as dairy, tomatoes, orange juice, soy and rice cereal were listed as “triggers” for reflux symptoms.

A trusted and supportive health or medical practitioner was often reported as critical to helping parents feel that they had some control over the management of the condition and the ability to alleviate the child’s pain and distress. For example, respondents said:

“It took allergy testing and a paed’s allergist to give us our lives back and begin to coordinate quality health care for my children.”

“The health practitioner who saved our lives was the dietician, not only guiding me on what to feed our daughter, but gave me the encouragement and support I so badly needed. That lady was a God send.”

However, many respondents felt that insufficient support was provided by health practitioners following diagnosis and initial treatment of GORD. More than 40% of respondents felt that the health practitioners involved in their child's care did not have a good understanding of infant GORD and its complications and did not adequately support them in caring for their child. Only 6% of respondents reported having a key health practitioner involved in coordinating the child's treatment and management. Many felt cast adrift and isolated with little advice provided about how to manage the day-to-day of the condition including limited sleep and ongoing unsettledness of the baby. Parents received few referrals for psychosocial support and ongoing care or follow-up was often inadequate. Parents noted:

“Shocking level of understanding but also empathy. I dare them to go one night in our house - they wouldn't be able to.”

“As first time parents, neither the GP or pediatrician really acknowledged or explained how stressful or the severity of what we had and would experience. Neither suggested support groups such as yourselves or any other resources, we were just eventually given a diagnosis and a script and sent on our way.”

Accordingly, parents frequently sought out their own information via the internet, joined support groups such as RISA and connected with other 'reflux parents' to access advice and assistance to manage at home. One respondent said that:

“... finding and joining RISA quite possibly saved my sanity at least. I will never be able to express how much appreciation I have for RISA.”

d. Disproportionate use of health services

Respondents reported using public and private health services a great deal in the infant's first year of life in order to obtain a diagnosis and treat GORD and its complications. They often saw and were dismissed by multiple health practitioners before receiving a diagnosis.

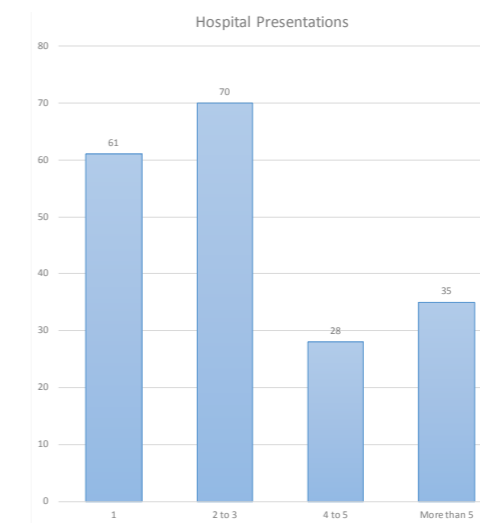
“Her issues were always put down to infant feeding issues, it wasn't until she was 13-14 months that her issues were taken seriously. My little girl fell thru so many gaps in the health system & was let down. She never should have gotten as sick as she did before being taken seriously.”

“There is a huge lack of understanding and misdiagnosis within the health profession. We were at breaking point by the time our pediatrician diagnosed and gave a treatment plan. I lost all faith in child health clinics as a result - they need to be trained in the symptoms and treatment path of reflux.”

More than 1 in 3 respondents attended a hospital emergency department (ED) in the first year in an effort to receive treatment for the child's condition, on average three times. The experience of parents attending ED was highly variable; some reported comprehensive assessment after staff were able to witness their baby “in action” while others were “brushed off” by “uncaring staff”:

“ED initially thought reflux but confirmatory ultrasound revealed pyloric stenosis. Lucky hospital was thorough as few risk factors for this. Reflux diagnosed after surgery.”

“I have nothing positive to say. I was turned away with the following cited to me: ‘it's colic’ ‘all babies cry’ ‘as a parent you are hyper-vigilant’ ‘dismissed as a virus’ ... ‘no appropriate referral to a paed's allergist/gastro’”



Number of hospital presentations in the first year

Over the course of the first year of life, many infants were seen and treated by a range of health care practitioners including a child health nurse, GP, paediatrician, paediatric gastroenterologist, paediatric allergist, speech pathologist, dietitian, psychologist and occupational therapist. 93% of respondents were initially referred to a general or specialist paediatrician to manage infant GORD and its complications and at least two health practitioners were involved in the ongoing care and management of the infant following diagnosis.

Parents reported that they regularly coordinated care for their child, possibly because they did not have a regular GP or paediatrician or the GP/paediatrician was willing or able to do so. Parents reported that this was a difficult and confusing exercise due to the varied and frequently inconsistent and conflicting advice provided.

“As parents, we were definitely the ‘managers’ of the situation with occasional medical input.”

“We have a GP, gastro paed and allergist. No one talks to each other about the multiple yet connected issues he has. It is so frustrating. I'm the coordinator - not medically trained and utterly sleep deprived.”

e. Impact of GORD on the child, parents and families

The survey results clearly demonstrate the devastating impact of GORD on the child, parents and family across all aspects of life including physical, emotional, social and financial. More than half of all respondents (286 people) reported that the impact of GORD on their quality of life was 9 or 10 out of 10 (10 being greatest possible impact on quality of life). Some of the specific impacts were: diagnosis of post-natal depression or anxiety (29%); increased strain on the primary relationship (68%); financial strain (32%); decreased participation in the workforce (29%); and poor physical health (19%). There were reports of marriage breakdown due to the demands of managing their child's poor health. Parent's reports of the first year were:

“It was absolutely horrific. Nothing could be done to settle our baby and he was irritable and crying non-stop. As parents, we quickly became exhausted and felt as though we couldn't leave the house. Relationships have suffered and we feel extremely anxious as a result of the unpredictability of each day.”

“The first year was really quite stressful and crappy. He was just unwell. He screamed a lot. Everyone assumed it was me, not him until they tried to settle him and failed. It was incredibly trying and isolating.”

“Reflux takes the happiness and joy out of having a baby and replaces it with stress and worry and fear and exhaustion.”

Parents reported that the dismissal of their concerns by health practitioners really affected them and their ability to cope and manage the child’s needs.

“I look back and think how much he had been in pain and we didn’t know how to help him, it makes me sad, but I remind myself that we did everything we could at the time and he was cuddled with love pretty much all the time for his first 3 months.”

“The pediatrician did not give us any helpful information and only caused harm and more distress. Health practitioners need to listen to families’ instincts and work with them, not disregard us.”

“In hindsight, his reflux was never under control or properly managed in that first year. We were just told that that was the only medication option we had and we just had to put up with it. No further referrals were made at that time.”

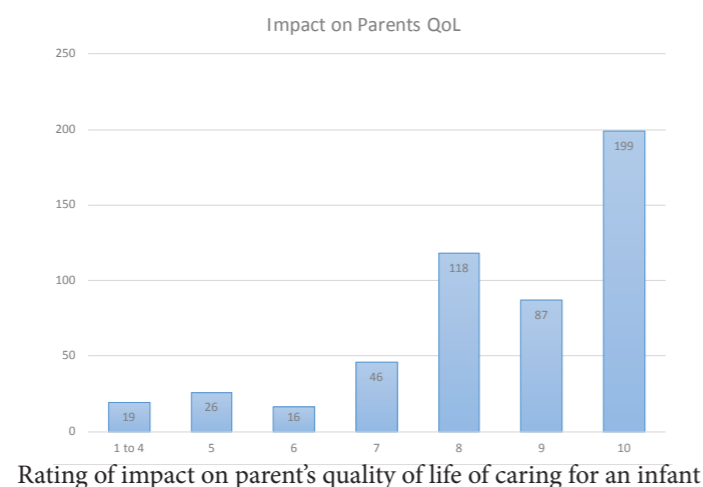
A further burden on parents in the first year of caring for an infant with GORD was the time and cost involved in attending appointments for many health practitioners and alternative therapists and cost of prescription and non-prescription medications. One in four respondents reported out of pocket health care expenditure of more than \$2000 over the 12-month period. This is likely to be an underestimate given that many respondents were caring for an infant aged less than 12 months. Parents described the first 12 months as:

“Expensive, frustrating, stressful, disappointing because treatments would always fail or only help for one or two weeks.”

“Expensive! Doctors, prescribed medications, alternative therapists and the supplements all cost a lot and puts a lot of strain on the family.”

Respondents also stated their fear at having another child with GORD. Just under half (45%) of respondents reported that having a child with reflux had affected their decision about whether to have more children¹³.

“I did want to have a second child in the hope that it would be a more enjoyable experience and that even if it had reflux I’d be able to manage it with the knowledge I had, but the second baby had far worse reflux and it was more traumatic given I hadn’t recovered from the first baby. No more babies after that.”



¹³ Respondents identified that they were undecided about whether to have more children or had decided not to have more children.

Discussion

The journey towards obtaining a diagnosis, treatment and management of GORD in infants in the first year of life is typically long and arduous. Parents report difficulty finding knowledgeable and empathetic health practitioners willing to treat the child’s symptoms. This impacts the child’s health outcomes at a time when they are developmentally vulnerable. It also affects the health and wellbeing of parents and the rest of the family as sleep deprivation, anxiety, guilt and distress take over. The effort of finding a solution to the child’s persistent issues influences all aspects of life including mental and physical health, personal finances and social life. Parents face isolation, undermined confidence, marital/relationship discord and may not feel able to bond with the infant.

There are many reasons for this but the fundamental issue appears to be the lack of knowledge and understanding among health practitioners and health services about the impact of GORD and its complications on infants and parents; and how to treat and manage the symptoms. There is wide variation in symptom presentation among infants with GORD and its complications and limited research and evidence in this area; with no diagnostic tests or endorsed clinical guidelines currently available in Australia. This makes it difficult for health practitioners to reliably and consistently diagnose, treat and manage GORD in infants and can compromise safety as demonstrated by the recent case of a reflux medication dosage error affecting a 6-week-old baby in Sydney¹⁴.

The signs and symptoms of reflux in infants lie on a continuum ranging from normal to severe. The diagnosis of GORD from reflux depends on the clinical judgement of the attending health practitioner based on the severity of the symptoms and the presence of ‘red flags’ such as failure to thrive or blood in the stool or vomit. A standard 15 minute GP or community health nurse consultation often provides insufficient time and opportunity for a full history and assessment of the child and parent. As a result, health practitioners may take ‘short-cuts’ and dismiss parents are being overly anxious or unprepared for ‘typical’ baby behaviour.

Health practitioners may be biased in their assessment of the child’s needs as a result of the beliefs such as:

- reflux is common but GORD is rare;
- the symptoms are distressing but rarely severe enough to warrant medical treatment; and that
- the best treatment is time as babies usually grow out of the condition by twelve 12 months of age.

This reflects an outdated attitude that some health practitioners and doctors may hold who see their role as treating babies with acute or critical needs rather than providing comfort and improving quality of life for infants with chronic and complex conditions. Parents often leave appointments with little more than empty reassurances to see them through the long days and

¹⁴ <http://www.smh.com.au/nsw/baby-grace-drunken-on-reflux-medication-after-sydney-gps-prescription-error-20170112-gtqp3s>.

nights with a screaming, difficult to feed baby who is unable to sleep in a safe position. This acute level of stress, in combination with a lack of appropriate support, may result in parents taking additional risks out of sheer desperation such as sleeping the baby against SIDs advice and pursuing non-evidence-based treatments and therapies.

Parents then run a gauntlet of appointments with medical and non-medical practitioners attempting to find empathy and a solution to their child's issues. Parents often see multiple GPs and health nurses and attend emergency departments in search of a diagnosis. Once a diagnosis is made, the child is often referred to a number of medical specialists and allied health practitioners depending on their condition. Treatment plans take time to have an effect and frequently do not resolve all the child's symptoms so parents seek out alternative therapies and treatments. Lack of communication and coordination between health care practitioners means that parents often shoulder the burden of managing care. The time, cost and impact of treating and managing infant GORD and its complications on parents and the health system is huge.

There is significant potential to improve this situation and reduce the burden on families and the health system without requiring a vast amount of new or ongoing expenditure. Of critical importance is investment in research to explore diagnostic and therapeutic approaches for infants with GORD and the longitudinal biopsychosocial impact of GORD on children and families.

An expert committee should also be established by the Australian Department of Health with parental input to develop Australian-specific guidelines. The guidelines should emphasise the need for empathy and support for parents and taking the time to listen to parents and address their concerns. They should raise awareness of the impact of untreated GORD on the child, parent and families. The guidelines can also support a better understanding among health practitioners of GORD as gateway disease to a range of other health conditions and complications including allergies, otitis media and sensory processing disorder. These conditions often have longer-term and more significant impacts on the child's health outcomes, development and potentially educational attainment resulting from pain, lack of nutrition, hearing difficulties, speaking and learning delays, behavioural problems and time spent out of school in hospital.

Conclusion

These preliminary results clearly demonstrate the sub-optimal experience of parents accessing health care in Australia to manage GORD and its complications in infants in the first year of life and the devastating impact of the condition on the child, parent and family. Further research and funding into treatment and management of GORD and its complications in infants is needed. The importance and value of health practitioners taking the time to listen, empathise and address parent concerns should not be under-estimated. Not only can this short circuit the pain and discomfort of the infant through earlier diagnosis and treatment, but the devastating impact of caring for an infant with GORD on parents' and families can be more readily addressed and reduced.

The survey results clearly demonstrate the strain that caring for an infant with GORD places on the parents' mental and physical health, relationships, quality of life and finances. Health practitioners need to sensitively recognise this strain and refer parents to, and support them to access, a range of services to address any psychosocial concerns and help them manage their caring responsibilities at home. When parents are dismissed as 'first timers' who are overstating symptoms and misunderstanding how babies should eat, cry and sleep, there is delay in diagnosis and treatment and increased harm to babies and their families. The burden on the health system, with related costs, are potentially enormous.

The experience of caring for an infant with reflux in the first twelve months is best summed up by this quote from a survey respondent:

“It was the hardest and most exhausting 12 months (and longer) of my life. No-one listened, I felt no-one cared and that I must be the most horrible and hopeless mother who couldn't help her child who was so quite obviously in pain. The ramifications of slow diagnosis and inadequate treatment is still a major issue for us now, as our son has severe oral aversions, sensory problems and psychological issues surrounding eating and food.”