A Review of Palliative Care and Support Services in South Tyrol for children and young people living with a life-threatening or life-limiting illness and their families.

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April 2013
“A review of palliative care and support services in South Tyrol for children and young people living with a life-threatening or life-limiting illness and their families.”

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Report prepared for:

Abteilung 40 - Bildungsförderung, Universität und Forschung
Amt 40.3 - Amt für Hochschulförderung, Universität und Forschung

Ripartizione 40 - Diritto allo studio, università e ricerca scientifica

Ufficio 40.3 - Ufficio per il diritto allo studio universitario, università e la ricerca scientifica

South Tyrol, Italy
April 2013
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Acknowledgements

Research is rarely a solitary process and is more often a collegial endeavour. Many people helped to bring this study to fruition and my most grateful thanks are due to my new colleagues and friends in South Tyrol.

This study was made possible by the generous support of the government of the Autonomous Province of South Tyrol through their initiative to promote the mobility and exchange of researchers between South Tyrol and the world. This is an exemplary programme that can only benefit South Tyrol and establish it as a leader in the promotion and sharing of international research and scholarship. I thank Dr. Daniela Ferraro, Dr. Rosa Pizzinini and Dr. Andrea Aldrighetto for making the administrative processes involved so smooth and painless.

My research partner in this work was the College of Healthcare Professions, Claudiana, in Bolzano. At every stage of the project, Claudiana and their executive of Dr. Herta Burger, Dr. Guido Bocchio and Dr. Eduard Egarter-Vigl have been unfailingly supportive and have generously enabled me to make the necessary four visits to South Tyrol to undertake the review. Claudiana has shown how higher education can work effectively with service providers in furthering meaningful, collaborative research, evaluation and service improvement. They will also have a key role in future paediatric palliative care education provision.

Within Claudiana I was fortunate to attract a ‘research team’ of exemplary health professionals who gave their time and energy freely to help me undertake this study - Dr. Maria Mischo-Kelling, Dr. Lukas Lochner, Dott.ssa Caterina Messerschmidt-Grandi and (MMK, LL and CM-G).

The various hospitals and health services in South Tyrol were welcoming and helpful in arranging visits, meetings and helping disseminate information about the study. I thank all the health professionals who participated in the survey and interviews and shared their knowledge and ideas with us. My thanks are due to Dr. Laura Battisti, Bolzano Hospital, who helped with the translation of the surveys into...
Italian and to Waltraud Mair who transcribed all the interviews with such care. Robin Dorigotti, English Teacher & Translator and two wonderful Claudiana students, Francesca Blasiol and Valentina Bampi also helped with Italian translation.

I also thank especially the parents who took part. I appreciate that these may have been difficult and often painful thoughts and conversations to have. However, the parents showed a generosity of spirit and took part so that their experiences and insights might help other families and improve services for children living with a life-threatening or life-limiting illness.

This has been a challenging project in many ways as I live in Australia and speak almost no Italian or German. My most grateful thanks are thus due to Dr. Maria Mischo-Kelling. From the early application phase of this project she has acted as colleague, translator, liaison-person, co-researcher and more. Without her continual support this project would not have been undertaken.

It was Florence Nightingale who made the famous comment that: “Reports are not self-executive”. In other words, reports do not implement themselves. People with vision, passion and drive do that. South Tyrol will now consider this report and its responses. It should initiate debate, consultation and discussion but it should also insist on action.

I wish South Tyrol and its future paediatric palliative care initiatives every possible success.

Professor Dr. Philip Darbyshire, Philip Darbyshire Consulting Ltd, April 2013
Contact: philip@philipdarbyshire.com.au
Executive Summary

Why this work is critical for policy and practice

Health services worldwide are becoming more aware of the need for critical review and evaluation. In the past, governments would create and build their programmes and services and merely ‘hope’ that people would find them valuable. Similarly, they were often created by policy makers and professionals with little or no attempt made at consultation with, or involvement from the community.

This world of healthcare is like shifting sands under our feet. Healthcare is changing, as are people’s expectations about how they should be involved. Ideas and principles of ‘patient participation’, community engagement and the growth of the active ‘service user’ or ‘health consumer’ and the ‘expert patient/parent’ movement are having a significant impact.

Ideas about ‘understanding patient experience’, ‘involving our consumers’, ‘having patients as partners’ and others would scarcely have been mentioned in any hospital or health service Senior Staff or Executive Group meeting even five years ago. This picture has changed dramatically, especially in the UK and increasingly in Australasia\(^1\) where these issues now sit (almost) side by side with the perennial issues of budgets, resources, staffing, targets and immediate health crises.

While no definitive ‘official’ figures exist about how many children in South Tyrol are living with a life-threatening or life-limiting illness or who are currently receiving palliative care, there are estimates that there may be approximately 100 such children with a variety of illnesses and conditions (Personal Communication, 2012), Dr. L. Battisti, Paediatric Oncology Department, Dr. G. Molinaro, Neonatal Intensive Care Unit - Bozen/Bolzano Hospital.)

South Tyrol has supported this study because it appreciates the importance of knowing how its health services are understood, perceived and experienced by the

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\(^1\) [http://en.wikipedia.org/wiki/Australasia](http://en.wikipedia.org/wiki/Australasia)
people most closely involved, in this case, parents of children with a life-threatening or life-limiting illness and the health professionals who care for these children and families. It does this because it appreciates the need to use these insights as an informed basis for future service developments in paediatric palliative care.

The key aims of this study:

- To ascertain from parental and health professional perspectives, if and how well the palliative and therapeutic care needs of parents, families and children affected by life-threatening or life-limiting illness are being met in South Tyrol.
- To produce a detailed, systematic account of family, child and staff perspectives and experiences that will enhance understanding of the ‘parents’ perspective’ of both caring for a child with a life-threatening or life-limiting illness and of any support or paediatric palliative care services received. Such an evaluative account will enable South Tyrol to further ground its health services in a more ‘evidence-based’ understanding of families’ experiences.

Timing of the study

The review commenced in January 2012 and data collection was completed by December 2012. The final report of the study was submitted in April 2013. The study was undertaken by Professor Philip Darbyshire (PD), an experienced researcher and international health consultant with expertise in paediatric palliative care service development in both Australia and New Zealand.

Information was collected through interviews and surveys from 59 people; parents, health professionals and other stakeholders. Participants contributed through a range of individual and ‘couple interviews’ and informal discussion. Parents of a child with a life-threatening or life-limiting illness, bereaved parents, children and
young people and health professionals, were also able to complete their own specific online survey.²

**Key findings**

**Parents**

1. Central to this entire study is that parents have experienced their world collapsing. This is not an exaggeration or being ‘excessively dramatic’. Parents have learned that their child has a life-threatening or life-limiting illness and that there is a strong possibility, if not an inevitability that their child may die before them. This understanding and how parents struggle to ‘manage’ this situation is the backdrop against which many of the findings can be understood.

2. Parents described experiences showing both the best and worst of South Tyrol’s and other places’ health services and health professionals. The best services and staff were caring, coordinated and acknowledged the parents as partners and experts regarding their child. The worst were fragmented, uncaring, self-centred, unavailable and made parents feel marginalised and more of a nuisance than an asset.

3. Despite all that we know about the vital importance of interpersonal relationships, care and compassion and sensitive communication between parents and health professionals, it was distressing to hear such vivid accounts from parents of encounters with health professionals that were simply ‘brutal’ and lacking in any empathy or understanding. Some parents’ experiences of being told their child’s diagnosis or of being forcibly separated from their child in hospital were particularly reprehensible.

4. Parents often described finding good care, a good service or a good health professional as being ‘fortunate’, - they were ‘lucky’. Perhaps they had met a particularly helpful health professional through a friend.

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² Copies of all of the surveys and information sheets used in the study, in both German and Italian can be found at: http://www.claudiana.bz.it/it/ricerca/aree-di-ricerca-e-progetti/helping-children-dare-una-voce-ai-bambini.html
or colleague or some other ‘unofficial channel’. Perhaps they had traveled widely to other centres or countries before finding someone ‘special’. Perhaps they had found someone ‘online’ who was outside of the health system. Perhaps they had a friend in a very senior position in a hospital or service who could help make ‘the system’ work better for them. While this may be good for the individual parent concerned, this should be an alarm bell ringing for a health system, if ‘luck’ determines its quality of care. Meeting health professionals who are valuable, helpful, empathetic, understanding, knowledgeable and who can work with you as a trusted partner in the care of your child should not be a gamble or a lottery. It should be an expectation and a minimum service standard.

A common theme in parents’ accounts was of having to “fight the system” and of always “fighting for their child”. This problem is not unique to South Tyrol or Italy but it is nevertheless a significant issue and an indicator that both interpersonal and systemic problems exist within a service provision. It is impossible to have a ‘patient-centred’ health system or a ‘family-centred’ paediatric palliative care service if parents are forced to see themselves, not as allies and members of the same team, but as an opposing army preparing to take on ‘the enemy’.

Most parents wished to care for their child at home. Certainly this is the case for parents whose child is living as ‘normal’ a life as possible with their life-threatening or life-limiting illness and hopefully having as fulfilling a childhood as possible. Home was also the preferred place however where the child was dying and no more curative treatment was available. It is such an understandable response that parents would want their child at home. To be ‘at home’ is, at its best, to be comfortable, to be among friends and family, to be relaxed, to be in a familiar place that moves to your rhythms and desires not those of a hospital ward or an ICU. In the most positive accounts, parents described how a flexible and creative service helped and supported them to adapt their homes and environments to make home care
possible. Yet for some parents, this wish to have the child at home was not facilitated and enabled by health professionals, rather it was resisted and opposed, at times even with legal threats. Such opposition is a violation of almost every accepted international standard for children’s palliative care.

(7) Caring for a child with a life-threatening or life-limiting illness or a child who is at home receiving palliative care when no more curative options exist is hard, hard work for parents. It is of course a ‘labour of absolute love’ and most parents very much want to have their child at home with them. While parents may not think of it as ‘work’, they are often carrying out 24 hour care for their child that many professional nurses would find tiring. Parents described their daily and nightly care routines as involving not only the ‘essential’ child care that any child will require but also NG tube-feeding, giving medications (perhaps IV), physiotherapy and movement exercises, oxygen and nebuliser administration, gastrostomy feeding, home ventilation and more. Parents need skilled, professional help and support if they are to carry out this dual role of nurse and parent.

(8) Parents need skilled help and support to care for their child at home. They especially valued the ‘nursing hours’ that enabled specialist nurses to visit their homes and to work as partners with them there in caring for their child. When such ‘nursing hours’ were available during the night, this often enabled the parents to have a rare uninterrupted night’s sleep.

(9) Children living with a life-threatening or life-limiting illness are first and foremost, Children. They have all the needs and developmental challenges that other children face but with the added complexity of either living with a very serious illness or sadly, or of being in the phase of dying from such an illness or condition. Children do not stop needing education, therapy and comfort when they are seriously ill or dying, especially if these are contributing to the child’s remaining quality of life.
Health professionals

(10) Health professionals felt that the term ‘paediatric palliative care’ remains very ‘emotionally charged’ and often has negative connotations among the people of South Tyrol, both parents and families, AND health professionals.

(11) Health professionals often agreed with parents regarding what they believed should be the hallmarks of an excellent paediatric palliative care service. They too emphasised coordination, collaboration, flexibility, specialist multidisciplinary expertise, good communication, easier access, and mutually respectful relationships.

(12) Health professionals generally supported the idea that a dedicated, specific paediatric palliative care service should be created in South Tyrol.

(13) There was support for the idea of a ‘focal point’, ‘contact point’ or case manager’ system that would make it easier for parents to ‘access’ and use ‘the system’.

(14) Most health professionals agreed that specific education and training in caring for a child with a life-threatening or life-limiting illness, in paediatric palliative care and in working in partnership with families (Family Centred Care), especially at home, was lacking in South Tyrol. Such ongoing professional education was seen as a high priority and an essential element of any future paediatric palliative care service.

Conclusion

(15) In some ways, South Tyrol is in a fortunate position in considering how to develop an excellent paediatric palliative care service. It has almost a ‘blank slate’ or ‘fresh canvas’ to work on, unencumbered by too many existing services, special interests, or powerful voices who would oppose change because; ‘We have always done things this way’.

(16) Realising the vision of a genuinely family-centred children’s service for paediatric palliative care and for children living with a life-threatening or life-limiting illness will require people with passion, drive and a
determination to think, create and work differently. The thinking that created the system of the past and structures of care of the present will not be able to create this service for the future. The new service and centre will require funding and resources but there should be much more creative and imaginative approaches taken to providing these. South Tyrol will need leaders and health professionals who are demanding of the highest standards and who are more resourceful, rather than those who only demand ‘more resources’.

(17) There is a clear momentum in international health care towards dedicated services for paediatric palliative care, supported by the National policy directives in Italy regarding the development of children’s palliative care services. This report should provide a platform for discussion of this vital issue and for a collaboratively agreed course of action towards the creation of such a leading, child and family friendly service.
Recommendations A-Z

“Make no little plans. They have no magic to stir men’s blood. Make big plans, aim high in hope and work.”

(A) Some parents reported receiving very good care and support during the different phases of their child’s life-threatening or life-limiting illness. There is much good work being done in South Tyrol but it remains ‘hidden’ or parents find it by ‘luck’ or influence. South Tyrol should identify, celebrate, share and build on these examples of good health professional practice and service delivery that are so appreciated by parents.

(B) South Tyrol should create a dedicated, specialist, clearly identifiable, multidisciplinary children’s palliative care service to support families who have a child with a life-threatening or life-limiting illness. This service should be available to support children and parents from the point of diagnosis, through treatment phases, through a child’s dying and death and subsequently during the family’s grief and bereavement. As with all good paediatric palliative care services this service will work in tandem and close partnership with children’s curative and active treatment services.

(C) This should not be a ‘death service’, it should be a ‘LIFE service’ focused on enhancing life, childhood and every aspect of quality of life for these children, young people and their families. This should also however be a service where death is NOT a ‘taboo’ subject. It should be a place where parents, the children and young people affected, their brothers and sisters and others can, when they wish, talk about dying and death in a safe and supportive environment.

(D) This service and its staff must be grounded in and exemplify the principles and practices of family-centred care (FCC), patient/parent-centredness (PCC) and best practice in paediatric palliative care as outlined in the European IMPaCCT Guidelines and other international standards.

(E) Excellent communication with parents, families and children should be a hallmark of this service and evidence of its successful adoption of FCC

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3 These recommendations are not listed in priority order. They are all important and all interdependent.

4 Daniel Burnham, American architect and city planner.
principles. Communication or relationship ‘breakdowns’ in this service should be investigated and treated as seriously as any adverse medical events.

(F) South Tyrol should have a physical ‘place’, ‘facility’ or ‘centre’ that is the hub and heart of its new paediatric palliative care service. This ‘place’ should be generally accessible from anywhere within the province. It does not have to be sited in Bolzano. The facility could be either an existing building that is renovated and designed to be a children’s service or a new purpose-built building.

(G) The new service and facility should be culturally appropriate, safe and welcoming for all families and cultures within South Tyrol. Families should feel ‘at home’ and ‘safe’ both in this facility and in their dealings with the team, regardless of their cultural or linguistic identification. No child or family should ever feel excluded from this service.

(H) This children’s service and facility must not be a ‘mini-hospital’ and should NOT be ‘owned’ by any particular hospital, service, or existing health professional group. Its ‘centre of gravity’ should be with the parents and children of South Tyrol that it serves.

(I) The service must not be an isolated entity, but should be closely networked and actively liaising with existing children’s health and social services, paediatricians, community family doctors and any other services that families will need to connect with.

(J) This facility should not be a ‘Children’s Hospice’. It is doubtful that South Tyrol could support such a residential facility, or that there is sufficient demand for one. The facility should have spaces for meeting with parents and families, for therapeutic and recreational activities, for ‘fun things’ for children, for allowing older children and teenagers, and siblings to meet socially, for enabling families to stay for ‘respite care’ and to allow end-of-life care for a child on the rare occasions when a family may request that choice.

(K) The new service should have a lean and minimally hierarchical management and reporting structure, perhaps directly from the Service Manager/Team Leader to the Health Board. There should be a broadly constituted ‘Governance Board’ chaired by an external person, whose role
is to support the development of the service and facility and to hold it accountable for working towards and meeting its goals.

(L) The service should not replicate a traditional ‘9am-5pm’ ‘office hours’ model or mentality, but should be flexible, creative and responsive enough to provide 24 hour care, advice and support for families when they need it.

(M) This service and facility should become the focal point and ‘first port of call’ for parents or health professionals seeking information, advice, support or advocacy about paediatric palliative care and the care and support of children living with a life-threatening or life-limiting illness.

(N) Most of the work of the new service will take place with families in their homes and in the community because this is where parents tell us consistently that they would prefer to be. This orientation towards working with parents and families as a peer and as a ‘guest’ in their home will require staff with particular skills, attitudes and a strong FCC and PCC philosophy. Not everyone who may wish to work in this service will be able to and team selection will be determined by much more than professional qualifications.

(O) The service should work with the whole family, not only the child with the life-threatening or life-limiting illness. Parents value counselling and the opportunity to talk about their child and their lives but so might grandparents. Brothers and sisters of the sick child have well recognised difficulties and issues and their plight has been overlooked for too long. This service will meet their needs also.

(P) This service and facility should have a genuine multidisciplinary team ethos and composition. It should not be created as simply another ‘medical clinic’ or ‘department’ of the health service’ operating under a traditional ‘business as usual’ model or medical hierarchy. The team members should be hired and roles allocated on the basis of their excellence and passion for this service. Staff should never simply be ‘sent there’.

(Q) The service and facility should attract and develop a trained ‘Volunteer Programme’ drawn from people in the community to support the work of the service’s multidisciplinary team and to be ‘ambassadors’ for the service within their local communities.
In considering and developing the idea of a dedicated paediatric palliative care service and facility for South Tyrol, existing parents, bereaved parents, the young people themselves who live with a life-threatening or life-limiting illness, health professionals and other ‘key stakeholders’ should engage together to discuss, consult and agree upon the kind of service and facility that will best meet families’ needs. These consultations should take place before any significant design or policy decisions are made.

This service should be a ‘research-active’ facility. Research awareness, research understanding, research use and research undertaking should be ‘built in’ or ‘hardwired’ into the thinking and practice of the service. Knowledge generation, evidence-informed practice and knowledge/research translation will be part of the everyday work of the service and not ‘icing on the cake’ or an afterthought.

The new service and facility will routinely collect, monitor, analyse and share the key data and information that will be required to determine how successfully it is meeting its goals and aims of serving the families of South Tyrol. Ongoing evaluation will be an integral part of the service’s functioning.

Continuing professional development and specialist education should be a priority for health and other professionals involved in paediatric palliative care and FCC for children with a life-threatening or life-limiting illness. The Claudiana is ideally placed to work with clinical and service colleagues and with the new paediatric palliative care ‘facility’ and its team to develop and offer such specialist courses. To develop an initial ‘critical mass’ of trained staff, South Tyrol Health should consider supporting staff who could access and undertake online Paediatric Palliative Care courses as other Universities internationally. Exchange programmes and ‘internships’ with existing paediatric palliative care centres of excellence would also be valuable for staff.

The new paediatric palliative care ‘facility’ and service should develop a local, national and international presence and profile and to become a leading centre in the care of children with life-threatening or life-limiting illness and their families. It should not be South Tyrol’s ‘best kept secret’.

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Such a presence should be established through conventional ‘scholarly channels’ such as conference presentations, research and publications, but also through community engagement events, media engagement and intelligent marketing based on a clear marketing and publicity strategy. The new service should also make full use of today’s and tomorrow’s communication channels, for example through its own self-maintained website, through the full range of Social Media platforms such as Facebook, Twitter, LinkedIn, YouTube and more. These avenues exist to be used, not to be feared.

The new service and facility should explore ways to engage the support of local and national businesses, companies or charitable foundations who would wish to be ‘industry partners’ in such a worthwhile new venture. For example, perhaps a car company such as Fiat, Audi or Toyota may wish to donate the centre’s cars that will be vital to enable the nurses to visit the families at home. Perhaps a major IT company such as Apple or Toshiba may wish to donate the computing equipment necessary for the service to videoconference and communicate easily with families at home, especially those in remote or mountain areas. Perhaps a charity or foundation such as the National ‘Lotto’ company may consider initial funding for the specialist children’s nurses within the team. (eg, in Australia the Jane McGrath Foundation began the ‘McGrath Breast Care Nurses’ service.)

Such a service and facility should be a technologically ‘smart service’ using the best available tele-health technology to enable communication and engagement with families, professional networks and key stakeholders. A family in a remote village or valley for example, should be equipped and enabled to use their laptop or tablet device to ‘meet’ or ‘speak’ face to face (using something like ‘Skype’ or Apple’s ‘FaceTime’) with staff at the facility or with other parents in the network.

South Tyrol’s new paediatric palliative care service must have parental involvement and participation deeply embedded and clearly demonstrable within every aspect of the service, from its inception and design, through to its everyday operation and its management and governance. This is not an ‘optional extra’. It is part of the collaborative, caring and family-centred ‘DNA’ of this service that will make it so valuable for these children and families. They deserve absolutely nothing less.
The Study Background, Context and Methods

I do not sleep and I cried a lot in the first year. (Int. #2)

Children’s palliative care: the policy background

It is valuable at the beginning of this report to focus clearly on the existential core of this review and that is care, love, support, loss and sadly, the possibility or actuality of the untimely death of a child or young person. Even the very mention of the word ‘death’ can be problematic. There are some who argue that Italy is a deeply ‘death-denying culture’, a country where even in a Hospice, “death is seldom talked about” and where:

“people accept the word ‘death’ only to hear that eventually it will be defeated”. (Campione, 2004, p.345, 348).

As one study participant commented:

The death of a child is a taboo for everyone if you are not working with this all the time. For the family doctor and for the parents it drives them crazy. (Int. #10)

Such a taboo that renders death ‘unmentionable’ may be changing however. A recent seven country European study focusing on citizens’ views of adult end of life care has found that adults are increasingly recognising the importance of death and dying and want quality of life to be a greater consideration than simply quantity (Daveson et al., 2013).

If ‘death’ is a problematic word so too, strangely, is ‘love’, especially for some researchers and academics. Gillis and Rennick argue about paediatric ICU that there is a:

“… remarkable absence of discussion of the importance of parental love in the pediatric intensive care literature, and that this silence has been to the detriment of both medical and
nursing pediatric intensive care practice”. (Gillis and Rennick, 2006)

They could just as readily have been writing about paediatric palliative care.

This report is emphatically about parental love for their child. It is about parents whose lives have been upended by the discovery that one of the most loved and cherished parts of their lives, their child, has a serious life-threatening or life-limiting illness. One of the terrifying implications of this life-threatening or life-limiting illness is that this child may die before their parents. Such a prospect can create feelings of parental and family grief and despair that are almost impossible for anyone to appreciate who has not been in such a position.

However, even in the midst of such a dark and seemingly hopeless situation, there are opportunities for hope, goodness and positivity. It will be reiterated several times in this report that there is no place in children’s palliative care for the nihilistic and hope-less notion that “there is nothing more that can be done” for a child or family. While the time may well come when there are no medical or curative treatments left to offer, there should never be a time when we stop caring for and supporting this child and family.

The child will continue to require effective pain and symptom relief and comfort measures. The child continues to be a child and needs all the things that remain important in a child’s world; family, friends, play, learning, and even fun and enjoyment within the limitations of their deteriorating condition.

The parents and child are not ‘doing nothing’ at this time. Besides the often relentless physical care and nursing work that these parents are doing, they are also, with the help and support of caring and creative health professionals, creating a community of memory (Bugge et al., In Press) around this child and helping to create what is often called, but which sounds paradoxical, ‘a good death’.

While it may seem impossible to understand the death of a child, we owe it to these parents, families and children to develop the best knowledge, understanding and...
services possible that will help and support them through this most difficult of life’s journeys.

This report explores a range of South Tyrollean parents’ experiences and perceptions regarding their child’s care and support through all phases of the illness trajectory. If this study of parents’ perspectives succeeds, it will enable the voices of parents who live with a child who has a life-threatening or life-limiting illness or who may have experienced the death of their child to be clearly heard and to inform future discussions and policy initiatives in this area.

The study should inspire policy makers, health professionals, parents and the whole community of South Tyrol towards action that will create a palliative care service and support network for children and young people which has as its foundation, a clear awareness and understanding of parents’, children’s and families’ lives and the support and service needs that they have articulated.

This report is written to provide an impetus for health professionals and service providers to encourage them to examine and discuss current paediatric support and palliative care services and their own professional practices so that these can be more closely aligned to meet parents’ expressed needs and wishes. That is the essence of a ‘patient and family centred’ child health service that has children and families at the epicentre of everything it does. The people of South Tyrol deserve nothing less.

Children die. This is a fact that we cannot ignore, that untimely death can be a part of even a child’s life. Some children’s deaths are as early as they are sudden, perhaps occurring in a neonatal intensive care unit where the baby has been born with a lethal abnormality (Balaguer et al., 2012; Bettini, 2012; Robertson et al., 2011; Jacobs et al., 2010). Some occur in childhood or adolescence (Wells et al., 2012; Cohen-Gogo et al., 2011; Montel et al., 2009) from a variety of life-limiting illnesses and conditions such as childhood cancers, metabolic disorders, degenerative conditions and of course injuries and accidents.
Adult palliative care services have developed more rapidly and comprehensively
than palliative care services for children and their families. This is not simply
because fewer children die than adults, but perhaps because the dying and death
of a child can be so much more emotionally laden and clinically demanding for all
concerned.

The phrase ‘Paediatric Palliative Care’ is almost a euphemism, a phrase that
stands for the underlying tragedy of a child’s dying and death. For some parents
and even some health services and health professionals, the words “Palliative
Care” are almost too distressing to consider or speak. As one child’s mother
commented in the ‘Maruzza Report’:\footnote{This excellent report is available in Italian here: \url{http://www.maruzza.org/new/wp-content/uploads/2012/07/I-FATTI.pdf}}:

“Palliative care is for old people who are dying… I don’t want to
have anything to do with it”. (Fondazione Maruzza, 2009, p.17)

The phrase ‘Palliative Care’ has (wrongly) been thought to mean that the child is
now quickly approaching death and that this is the ‘last phase’ of their lives. As one
parent commented about the phrase:

I: How have you coped with this word? (palliative care) What did you think when
you heard it?

P: Yes of course that was difficult at the beginning to accept that it actually is like
this. So for me it was hard, I must admit. (Int. #13)

A further, vital reason is perhaps because adult and paediatric palliative care
services are not ‘the same’. A children’s palliative care service is not simply an
adult service ‘scaled down’ for ‘little people’ (Langiano, 2012). Children and young
people have a host of differing needs, abilities, understandings and relationships
that require a tailored ‘paediatric’ approach.

It is never, ever the case that children’s palliative care means: “There is nothing
more that we can do”. On the contrary, children’s palliative care means that there is
everything possible to be done - everything to help and support the family and
child, everything to ensure the child’s comfort and dignity, everything to minimise
their pain and suffering, everything to help them experience as ‘normal’ a life and childhood with their family as they can, everything to ensure the best quality of life possible. There is also, as O'Shea and Kanarek (a paediatric palliative care nurse and a bereaved parent) explain, a need for professionals to:

“Be capable of bearing witness to a dying child and a grieving family. Simple presence - staying close and saying nothing - can sometimes provide more comfort than words”. (O'Shea and Bennett Kanarek, 2013, p.39)

While paediatric palliative care services in many parts of the world may have been slow to develop (Knapp et al., 2012), considerable progress has been made internationally in determining and describing the service standards and principles that should underpin the development of future paediatric palliative care services.

International agreement on children’s palliative care

For governments, policy makers and child health services seeking to understand this policy background and to develop ‘best practice’ children’s paediatric palliative care services, valuable advice and information is available. Twenty years ago, The International Work Group on Death, Dying, and Bereavement (International Work Group on Death Dying and Bereavement, 1993) produced a position statement on Palliative Care for Children which asserts the importance of a palliative care service for all children and their families. It is as relevant and important now in 2013 as it was in 1993. This group stated that this service should be:

“An individualised, coordinated system of health care which provides continuity of services between the hospital, the home and the community [which] must be developed as soon as feasible after diagnosis”. (International Work Group on Death Dying and Bereavement, 1993)

They also state that:

“This coordinated system must be maintained throughout the illness and death, with follow-up support for family members after death. It is mandatory that this system of care be made
accessible to all children and their families regardless of race, sex, culture and/or ability to pay. The system of care must be flexible in providing services in the community, the home, and the hospital". (International Work Group on Death Dying and Bereavement, 1993)

Terms and definitions

There is some interchangeability and possibly confusion between terms such as ‘Palliative Care’, ‘Terminal Care’ and ‘Hospice Care’ within the literature, and within palliative care services themselves. It is perhaps understandable that parents and families could be confused by these terms.

In this study I have adhered to the definitions and understandings of children’s palliative care as outlined in the “IMPaCCT: standards for paediatric palliative care in Europe” document (Craig et al., 2007; European Association of Palliative Care (EAPC), 2007). (The IMPaCCT Standards are also available in both German and Italian (European Association of Palliative Care (EAPC) Taskforce, 2007a; European Association of Palliative Care (EAPC) Taskforce, 2007b). This is currently the definitive standards document for children’s palliative care services and defines and explains Paediatric Palliative Care following previous WHO conventions thus.

Definition of paediatric palliative care

The World Health Organisation (WHO) definition of paediatric palliative care was adopted by IMPaCCT and these principles apply to cancer and other paediatric disorders:

- Palliative care for children is the active total care of the child's body, mind and spirit, that also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Healthcare providers must evaluate and alleviate a child’s physical, psychological and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community...
resources; it can be successfully implemented even if resources are limited.

- It can be provided in tertiary care facilities, in community health centres and even in children's homes. (European Association of Palliative Care (EAPC), 2007, p.2)

We also follow the IMPaCCT document in talking about ‘life-threatening’ and ‘life-limiting illness’, where:

“Life-limiting illness is defined as a condition where premature death is usual, for example, Duchenne muscular dystrophy.” (European Association of Palliative Care (EAPC), 2007)

Life-threatening illness is one where there is a high probability of premature death due to severe illness, but there is also a chance of long term survival to adulthood. For example, children receiving cancer treatment or admitted to intensive care after an acute injury.” (European Association of Palliative Care (EAPC), 2007, p.2)

The widely used ‘Goldman classification’ (Goldman et al., 1990) describes four possible illness pathways that a family may experience depending on their child’s diagnosis:

1. Diseases for which curative treatment may be possible but may fail (e.g. cancer)

2. Diseases in which premature death is anticipated but intensive treatment may prolong good quality of life (e.g. cystic fibrosis)

3. Progressive diseases for which treatment is exclusively palliative and may extend over many years (e.g. neurodegenerative disorders)

4. Conditions with severe neurological disability that, although not progressive, lead to vulnerability and complication likely to cause premature death (e.g. severe cerebral palsy).
In this report I use the term palliative care to highlight the purposive and positive nature of palliation and because palliative care does not necessarily imply an imminent death.

**Children’s palliative care in Italy and internationally**

**Sourcing and searching the relevant literature**

The literature review for this study commenced prior to the submission of the Researcher Mobility proposal and new research and works have been continuously added and incorporated throughout the project. The literature search encompassed both peer-reviewed journals, books, official reports and other published literature. Electronic database searching, contact with Italian and international experts in the field, plus internet searches targeting individual ‘palliative care organisations’ and government websites were among the key approaches used to identify and obtain literature relevant to this study. The literature search methodology incorporated these strategies:

1. **Electronic database (ED) searches.** Numerous subject and text words related to children’s palliative care and its associated terms were used in searching a range of electronic databases in subject fields such as Nursing, Medicine, Social Sciences, Psychology, Health, News & Current Affairs and Child Development. Searches were predominantly in English but searches were undertaken for literature specifically related to children’s palliative care in Italy and written in either Italian or German.

2. **Internet searches.** Key organisation and government websites were searched both internationally and in Italy. Free text internet searches were also undertaken, using the Google search engine and Google Scholar, Journal Genealogy. Reference lists of key journal articles from other key papers and reports were scanned to identify further studies of interest. Consultation with specialist palliative care, children's palliative care and other advisers. Our research team was able to identify, and consult with colleagues involved in children's
palliative care who suggested additional articles and reports relevant to the study.

The international literature on paediatric palliative care is diverse and growing. In the early days of palliative care’s development, children and young people were relatively invisible among the adult-related work. In recent years however, the paediatric palliative care field has matured and developed to the point where there is now a wide body of research and practice-based literature devoted to most aspects of palliative care for children, for example, policy issues, ethics, clinical care, service provision, program evaluation and specific research approaches.

Palliative care services for children and young people are a comparatively new development in medical, health and social care. They have generally been slow to develop in most countries of the world and have usually lagged behind the creation of adult palliative care services. In Italy, it has been suggested that there is a considerable reluctance among both health professionals and patients and families to even talk about issues such as prognosis, dying and death. Within such a culture of denial, palliative care can be seen as a ‘giving up’, a ‘defeat’ and a ‘failure’. As Floriani notes of this Italian context:

“Palliative care is seen as a defeat and, as such, is to be postponed for as long as possible”. (Floriani, 2009, p.205)

Palliative care is premised upon the knowledge that while there may be ‘nothing more that can be done’ in a curative sense, there is still a great deal which should be done to support the child’s and family’s quality of life. As the World Health Organisation definition of palliative care states:

“[It is] The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families”. (Davies and Steele, 1996)
Children’s palliative care in Italy

General Palliative Care in Italy has been slow to develop due to a combination of numerous factors, both cultural, political and medical. In a witheringly critical assessment, Toscani argued that:

“In truth, the Italian health system did not provide palliative care. Nobody even knew the meaning of the word ‘palliative’, and the attitude of physicians toward the dying was either an embarrassed: ‘I am sorry, but unfortunately there is nothing else I can do’, or unashamed over-treatment (‘Terminal patients don’t exist. An oncologist who thinks they do is a depressed one, and he had better change job!’)” (Toscani, 2002, p.177)

Children’s palliative care has also developed more slowly in Italy than in other European countries (see eg, Floriani, 2009). However the work of Italian paediatric palliative care specialists and researchers such as Prof. Franca Benini and organisations such as the Maruzza Foundation have helped raise the profile of paediatric palliative care in Italy (Benini et al., 2011b; Benini, 2011; Benini et al., 2010; Benini, 2010; Benini et al., 2007; Benini, 2004; Ferrante et al.). In the UK for example, there is a well established network and organisation of Children’s Hospices in addition to other dedicated nursing and community care services such as the ‘Diana Nurses’ (Carter, 2005).

The ‘Maruzza Report’ for example, notes that:

“It is urgently necessary to program and organise paediatric palliative care services that adequately address the needs of children and families. It is also necessary to provide adequate education and training for those providing palliative care services”. (Fondazione Maruzza, 2009, p.31)

Italy is keen to refine, improve and further develop its Paediatric Palliative Care and Bereavement services to benefit families, children, staff and the wider community alike. This proposed study thus aligns with current National Health Policy, as noted by Benini et al:
“In the decree of the President of the Republic of 7 April 2006 on the adoption of the Italian national public health plan for 2006–2008 (published in the Official Gazette n.139 of 17 June 2006), the strategic objective 3.10 states that, "particular attention must be paid to the need for palliative care in neonatal, pediatric and adolescent age." (Benini et al., 2008)

Parents, professionals and health care providers are usually confident that they provide the most appropriate services for children with life-threatening conditions and their families. However, the voices of the most important people concerned - the children and parents, often remain unheard (Swallow et al., 2012; Sheetz and Sontag Bowman, 2013; Vollenbroich et al., 2012; Robert et al., 2012; Doig et al., 2009; Hinds et al., 2009; Meert et al., 2008; Davies et al., 2007; Wilkinson et al., 2007, Nuutila and Salantera, 2006; Heller and Solomon, 2005; Darbyshire et al., 1997).

This study redresses some of this imbalance in our research knowledge by involving parents directly to discover their perceptions and experiences of having and caring for a child with a life-threatening or life-limiting illness.

In a recent 2010 study, Beretta et al noted that further research is needed in Italy to determine parents’ experiences of the paediatric palliative care services that their child received:

“It would be useful to know how parents perceived the quality of the palliative care their child received”. (Beretta et al., 2010, p. 90)

This study begins to answer this question by presenting these ‘parental perspectives’ of accessing and using such paediatric palliative care and other support services in South Tyrol and elsewhere.
Research approach and methods

The aims of this study

- To ascertain, from parental and health professional perspectives, if and how well the palliative and therapeutic care needs of parents, families and children affected by life-threatening or life-limiting illness are being met in South Tyrol.
- To discover any barriers or facilitating factors associated with the provision of high quality palliative and/or supportive and therapeutic care as perceived by both family and health care providers.
- To ascertain from the families’ perspective what supports, help, information and services they particularly value in helping them manage their child’s palliative and/or supportive or therapeutic care.
- To produce a detailed, systematic account of family, child and staff perspectives and experiences that will enhance understanding of the ‘consumer perspective’ of children’s palliative care and bereavement support. Such an evaluative account will enable South Tyrol’s health services to further ground its services in a more ‘evidence-based’ family experience.
- To inform and drive the development of improved palliative care, therapeutic and bereavement support services for families and young people by providing an evaluative research basis firmly grounded in their articulated experiences.
- To enhance the reputation of South Tyrol Health Services, Claudiana College and their related stakeholders as organisations that value, promote and undertake systematic evaluation and research.
- To promote the research benefits of collaboration and cooperation with various other colleagues, sectors and services.

Recruitment and invitation of participants

Purposeful sampling was used to invite the participation of parents, carers, young people and health professionals in South Tyrol. Participants were invited to take part in the study who had direct experience of caring for children with life-limiting or...
life-threatening illnesses and who were willing to share and discuss these experiences.

**Exclusion criteria**

The main exclusion criteria were a parent(s), child’s or staff member’s decision not to participate, which was immediately respected and taken as final. We liaised closely with hospital and health service staff to be aware of any children, families, volunteers or staff who, for whatever reason should not be approached about the study. Their advice as to the circumstances that might make an approach to a particular family, for example, untimely or intrusive was always heeded.

**Obtaining participants’ views: online survey and personal interviews**

**Why on-line questionnaires?**

For this survey, we used the online survey programme ‘SurveyMonkey’ and created FOUR distinctive on-line questionnaires using a cross-sectional self-completion design (Bryman 2004). One questionnaire was for children (IT2, D2) and young people living with a life-threatening or life-limiting illness. One questionnaire was for parents whose child currently has a life-threatening or life-limiting illness (IT4, D4). One questionnaire was for bereaved parents (IT6, D6) whose child had died following a life-threatening or life-limiting illness and one questionnaire was for Health Professionals and other key stakeholders (IT8, D8) involved in caring for children with life-threatening or life-limiting illness.

Self-completion questionnaires are convenient for respondents to complete in their own time and enable a large number of potential participants to be reached during any given time period. Survey data collection occurred between June to December 2012.

On-line questionnaire and survey tools have proved to be a valuable approach in survey methodology (Wright, 2005). On-line data collection instruments have

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6 [http://www.surveymonkey.com](http://www.surveymonkey.com)
advantages in cost-effectiveness, offering savings in postage costs and in reduced time required for manual analysis. As web survey technology has improved, it has also become easier for the ‘average computer user’ to be able to design and launch surveys without the need for knowledge of complex internet and computer programming.

As the growth in computer use continues to rise (Madge et al., 2004) ‘going online’ is becoming an increasingly common parental response. Parents are searching for information, they are communicating with other parents and professionals and they are using the worldwide web as a vehicle for advocacy (Knapp et al., 2011a; Knapp et al., 2011b). For the purposes of this survey, it was important to note that many parents and carers of children with a disability or serious illness are “frequent users” of computers and the internet, especially at home (Blackburn and Read, 2005; Byczkowski et al., 2011).

We were of course aware that some potential respondents may not have computer access or may prefer the ‘pencil and paper’ approach and so paper copies of any of the questionnaires could be provided by the Project Team if a person did not have access to a computer. However, no requests for ‘paper copies’ were received.

Preparing the questions

The questions for the various questionnaires were prepared by PD and translated by MMK, LL and CM-G in response to the overall aims of the project, suggestions and findings from relevant current literature and from experience of conducting previous surveys in this topic area in other countries. The questionnaires used a combination of closed and open questions to allow respondents to rate and describe their levels of satisfaction with the children’s palliative care and other support services available in South Tyrol and to provide comments to clarify or expand their views. A copy of each of the questionnaires and information sheets that were used, in both German and Italian, is available at the Claudiana Web site
A total of 39 participants completed the online survey: This comprised 30 health professionals, eight parents and one young person.

Figure #1: The online survey participants:

Obtaining participants' views: the interviews

The study's survey data was complemented by the undertaking of a series of qualitative interviews with both parents and health professionals. A predominantly qualitative approach was used because this review’s research questions were best approached interpretively. Each of the key groups in the study; young people, parents and health professionals were offered the opportunity to speak with us, either individually, as a couple or in small focus groups.

Table #1 shows the relevant details of both the participating parents and health professionals.

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Nine parents and eleven health professionals took part in the interviews. One participant was interviewed twice, as both a parent and as a health professional.

Table #1: Parent and Health Professional Interviews.

<table>
<thead>
<tr>
<th>N°</th>
<th>Participant(s)</th>
<th>Place</th>
<th>Duration</th>
<th>Diagnosis</th>
<th>Age at diagnosis</th>
<th>Child</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Parent/H.P.*</td>
<td>Office</td>
<td>2 h</td>
<td>Childhood cancer</td>
<td>4 yrs</td>
<td>died</td>
</tr>
<tr>
<td>2</td>
<td>Parents</td>
<td>Home</td>
<td>1h 45m</td>
<td>Genetic disorder</td>
<td>6 m</td>
<td>alive</td>
</tr>
<tr>
<td>3</td>
<td>Nurse</td>
<td>Office</td>
<td>2 h</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>4</td>
<td>Parents</td>
<td>Home</td>
<td>3h 08m</td>
<td>Childhood cancer</td>
<td>4 yrs</td>
<td>alive</td>
</tr>
<tr>
<td>5</td>
<td>Nurse</td>
<td>Claudiana</td>
<td>1h 17m</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>6</td>
<td>Physician</td>
<td>Claudiana</td>
<td>1h 24m</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>7</td>
<td>Nurse</td>
<td>Office</td>
<td>52m</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>8</td>
<td>Nurse</td>
<td>Office</td>
<td>59m</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>9</td>
<td>Mother</td>
<td>Home</td>
<td>1h 45h</td>
<td>Childhood cancer</td>
<td>2 yrs (approx)</td>
<td>died</td>
</tr>
<tr>
<td>10</td>
<td>Physician</td>
<td>Office</td>
<td>1h 22m</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>11</td>
<td>Physician</td>
<td>Office</td>
<td>57m</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>12</td>
<td>Physician</td>
<td>Office</td>
<td>55m</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>13</td>
<td>Parents</td>
<td>Claudiana</td>
<td>1h 12m</td>
<td>Metabolic disorder</td>
<td>6 m</td>
<td>died</td>
</tr>
<tr>
<td>14</td>
<td>Physician</td>
<td>Claudiana</td>
<td>43m</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>15</td>
<td>Mother</td>
<td>Home</td>
<td>1h 59m</td>
<td>Genetic disorder</td>
<td>1st months</td>
<td>died</td>
</tr>
<tr>
<td>16</td>
<td>Mother</td>
<td>Home</td>
<td>1h 14m</td>
<td>Congenital disorder</td>
<td>at birth</td>
<td>alive</td>
</tr>
<tr>
<td>17</td>
<td>Psychologist</td>
<td>Claudiana</td>
<td>55m</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>18</td>
<td>Parents and child</td>
<td>Home</td>
<td>2h 02m</td>
<td>Genetic disorder</td>
<td>3 w</td>
<td>alive</td>
</tr>
<tr>
<td>19</td>
<td>Mother</td>
<td>Claudiana</td>
<td>37m</td>
<td>Genetic disorder</td>
<td>6 yrs</td>
<td>alive</td>
</tr>
</tbody>
</table>

(As PD does not speak Italian or German, he was accompanied in each interview by a co-researcher (MMK, LL, CMG) who speaks Italian/German and who undertook the ‘translation’ during the interviews.)

The interviews were conducted as closely as possible to natural, informal conversations, which allowed the participants to speak freely about their most salient experiences and perceptions related to children’s life-threatening or life-
limiting illness, children’s palliative care and/or bereavement and the death of a child. There is no prescriptive interview schedule, as a reflexive 'openness' is essential in such qualitative evaluation. There were however ‘generative’ or ‘trigger’ questions related to the central evaluation aims and to the broad online survey questions that were modified for each participant group. For example, we may have begun an interview by asking parents, “Can you tell me about when ‘Maria’/‘Mario’ first became ill?” or “Would you like to start at the beginning and tell me about ‘Maria’s/Mario’s’ initial illness and diagnosis?” Specific issues would then be broached by, eg, “I have spoken to lots of parents in Australia about “X”. Was that an issue for you here in South Tyrol”? or, “Several health professionals in the survey described “X” as being a problem in helping these families. How has this worked for you”? Questions were always ‘focused but roomy’ and never blunt or confrontational. Interviews generally lasted between approximately 35-180 minutes.

As part of the careful explanation of the research given and as part of the ongoing informed consent process, participants were assured that they could choose not to discuss any issue or to stop an interview at any time and for any reason. The interviews were carried out at a place where people felt most comfortable, whether that be their workplace, the Claudiana or the family home.

Recording data

The essential data for this study is the online survey and the recorded and transcribed interviews with the participants. The survey website (via www.surveymonkey.com) and the survey responses were encrypted, password protected and accessible only to PD, MMK, LL and CM-G.

Recording of the interviews was essential to fully and accurately capture the data. Note taking during interviews could not achieve this level of comprehensiveness or accuracy and would also impair the interviewer’s ability to concentrate on the vital matter of the interview dynamics and the participants’ experiences that were being shared. Interviews were recorded using a small, unobtrusive digital voice recorder and a second recorder as ‘back-up’. My long experience in recording qualitative interviews suggests strongly that recording is not a problem for participants if the
issue is discussed openly and the value of obtaining the best record possible of the interview is clarified. Interviews were accurately transcribed by an experienced medical PA/secretary. At this stage all identifying names were removed.

Ethical considerations

Formal ethics approval

This study received formal ethics approval from the Ethics Committee of the South Tyrol Health Department on 25th January 2012.

Protecting confidentiality

The following steps were undertaken to protect the confidentiality of participants:

- All participants are anonymised in this report, eg “As one father commented….” “I think that nurses should…. ” (Interview #4).
- All children mentioned will be referred to as either ‘Mario’ or ‘Maria’.
- The gender of participants may have been re-assigned if this was felt necessary to avoid identification, e.g. We may indicate Mother instead of Father.
- Where participants make named reference to any other person these will also be replaced by pseudonyms, eg ‘Maria’/‘Mario’ or Dr.X at the Hospital X in City Y in Country Z helped us by…” (Interview#2).
- Names of places, suburbs and other locations which might compromise the confidentiality of the participant are omitted and mock place names used, e.g. (City X).

All questionnaire responses were anonymous and informed consent to participate in the survey was implicit in the respondent’s decision to complete the survey online. The on-line questionnaires were designed and administered using www.surveymonkey.com. Through a dedicated web page hosted within the Claudiana College Website Interested parents, children and health professionals

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could access detailed information sheets describing the study and answering any possible questions that they may have had. If, having read this information, they were then prepared to complete their respective survey, they could do so from the same web page.

Individuals who completed the questionnaire remained anonymous and entered limited and de-identified demographic information. SurveyMonkey is a survey ‘clearinghouse’. Except for the member who has the password no other person has access to the results.

Avoiding potential harm

Our approaches to recruiting and interviewing in this study were driven by sensitivity, openness and respect for people’s right to choose whether or not to participate. Palliative care and bereavement involving children are always sensitive issues and can be uncomfortable to discuss. However, the research in this area consistently shows that people value and appreciate the chance to ‘talk about’ their child’s illness and even their death. Service users also consistently report that they expect to be and value being consulted about service provision. Bereaved parents and parents of children with a life-threatening or life-limiting illness often have a powerful sense of altruism whereby they value the opportunity to share their experiences in such a way that might ‘make things better’ for other parents who are experiencing ‘what they have gone through’ (Gysels and Shipman, 2008).

Funding issues

The study was funded by the government of South Tyrol through the ‘Incoming Researcher’ programme. Supplementary funding covering PD’s travel costs and ‘In-kind’ support for the project was also provided by the Claudiana. No payments were made to study participants and we did not consult or access any medical or health records during this study.
Analysis of results

Survey data analysis

One advantage of an on-line survey tool such as Surveymonkey is that all completed survey questionnaires are received and collated by the Surveymonkey website in ‘real time’. This means that at any given point in the survey, the Surveymonkey password/license holder can check on the progress of the survey and see, for example, how many completed questionnaires have been received. It is also possible to see a descriptive depiction of frequencies of responses, collated ‘open responses’ to particular questions and more. Open-ended and ‘comments’ responses in the surveys were treated as qualitative research data, collated and then analysed in a similar manner to the interview data, informed by both content and thematic analysis approaches (Boyatzis, 1998; Hsieh and Shannon, 2005).

Descriptive data from particular survey questions are presented as graphs where this will help illustrate participant responses. The focus here is on surveys D8 and IT8, the health professionals and on D4 and IT4, the parents of a child who has a life-threatening or life-limiting illness and D6, the bereaved parent.

Interview analysis and interpretation

Analysis was informed by my previous experience in conducting other studies related to parents’ and children’s experiences, especially related to hospitalisation, paediatric palliative care and grief and bereavement (Darbyshire et al., 2013, Bugge et al., 2012, Moran et al., 2011, Bugge et al., 2009). The principles and approaches of interpretive phenomenology, content and thematic analysis were also used, in that we sought to discover parents’ views and perceptions of specific issues concerning their and their child’s lives, but also the more phenomenological aspects of what it means to be the parent of a child with a life-threatening or life-limiting illness in South Tyrol.

The interview data was questioned, coded and considered in detail to identify and explicate salient themes, patterns, similarities and dissimilarities, observations,
events, perceptions, understandings and practices which illustrate parents’ and health professionals’ perceptions, views and experiences of existing services for children with life-threatening or life-limiting illness. In addition, views and ideas regarding desired improvements in service provision were also captured and reported.

The research team in South Tyrol and Prof Darbyshire in Australia both conducted content and thematic analysis of the interviews using specialist software to assist with data management (‘MaxQDA’ and ‘Dedoose’ respectively). The researchers compared notes electronically and again ‘in person’ when Prof Darbyshire returned to Bolzano in April.

In presenting the data and findings from this study, it is important that these are grounded in the actual data of the surveys and interviews. For this reason, each interpretive ‘theme’ reported is supported by relevant quotations, comments or figures taken directly from the interview transcripts or survey responses. The quotations and extracts cited have been preserved as close to their ‘verbatim’ transcription as possible. Where an exact translation into English was difficult, the researchers checked and discussed the quotation and its context in the interview to determine how best to express it in English to convey the meaning as faithfully as possible. Participant quotes may not read as grammatically correct in places. They are however, conversations, and the more salient issue in this study is the perceptions and meanings that are conveyed.

To distinguish interview participants’ survey or interview quotes from quotes taken from ‘the research literature’:

Participants’ quotes will be shaded in a block quote like this, regarding either the survey or interview number, eg (survey) or (Int. #4)

Research Literature “quotes” will be set out like this. (Author, date)
The Parent Survey Questionnaire

The parents who completed the survey

The specific survey for parents of a child with a life-threatening or life-limiting illness was available in both German (D4) and Italian (IT4). This online survey was accessed by seven parents. Six completed the version in German and one completed the Italian version. Four respondents were mother and three were fathers. Four respondents completed the survey fully and three partially completed it (i.e., they did not answer all the questions, as they were entitled to do). One parent completed the survey for bereaved parents in German (D6). All surveys were completed between June and December 2012.

Demographic details of parents

All respondent parents lived in South Tyrol. All respondents who indicated their nationality identified as Italian. Four were mothers and three were fathers. The parents’ ages ranged between 36 and 48 years. All respondents were married. A note on the gender of respondents is useful at this point. Research in paediatric palliative care is often criticised for the gender imbalance of participants, where, for several reasons, mothers heavily predominate (Macdonald et al., 2010). In this study, there is a more balanced representation of both mothers and fathers with five fathers and eight mothers being involved in the interviews and four mothers and three fathers completing the survey.

Demographic details of their children

Four of the children described were male and three were female. Six of the children being cared for were aged between 0-5 years and one was a teenager between 15-18 years old. Three of the children had siblings and four were an ‘only child’. All the younger children had been diagnosed with their condition between the age of 0-5 years while the teenager had been diagnosed later at between 15-18 years old. The respondent parents’ children had a range of conditions including childhood cancer, genetic and degenerative disorders.
The Parent Interviews

This section of the report provides detailed accounts and interpretations of parents’ experiences of caring for and providing care for their seriously ill child. It is often difficult for parents to speak openly and honestly about the fact that their child has a life-threatening or life-limiting illness, about the possibility that their child may die before them or about their child who has already died. Parents’ reasons for consenting to participate in this study were always, a desire to help others, and in particular, other parents and children who may now find themselves in the same situation. We hope that health professionals and service providers will honour the parents’ wishes by reading this report and that they will have the opportunity to deepen their understanding of ‘what it is like’ for parents to care for such a child.

‘When your world collapses’: finding out that your child has a life-threatening or life-limiting illness

So I know she’s going to die before me. (Int. #2)

Parents often describe how having a child is so much more than simply gaining an additional family member. Having a child and becoming a parent are world defining events that shift our centre of gravity and forever reshape our relationships with each other and the world. This parent expressed it well:

Your job does not matter, the money does not matter, does not matter at all, the important thing is to be able to make sure that this child will grow up and can live as good a life as possible with the illness they have. (Int. #18)

We also tend to assume that our children will be born healthy and that life-threatening or life-limiting illness is something that will not touch our world. Unfortunately for some families, it does. As this parent explained:

It was a tragedy in the sense that you assume that your child will be born healthy. And that is stupid we know, because you can never be that sure. We all take for granted that our children will be born healthy, but it is not like that. (Int. #18)

So too, when parents discovered that all was not well with their child and learned of the seriousness of their illness or condition, their worlds again changed beyond...
recognition and so began the course of their ‘new lives’. Many parents, like these, described this as their world ‘collapsing’ below their feet and of the ‘bottom falling out of their world’:

When you get the diagnosis, the world collapses. In that moment, it is like the end of the world (Int. #1)

… It was as if the ground under our feet was pulled away completely. I was standing outside myself and looking at myself because you don’t understand what’s suddenly happening. (Int. #9)

I felt the ground fall away under my feet (Int. #4)

These parents were entering ‘a foreign country’; a world of hospitals, clinics, tests, treatments, equipment and procedures; a land of fear, uncertainty, pain, distress and upheaval. As these parents explained: this is a world that required them to rethink and rebuild almost every aspect of their lives:

You find yourself at any moment where you have to rebuild your entire life. (Int. 18)

The growing awareness that ‘there’s something wrong’

For some parents, the onset of their child’s illness or condition was so dramatic and obvious that investigation and diagnosis were rapid processes. These parents describe being a ‘normal’ parents and family one day, and being the parents of a very seriously ill or dying child the next day. As this parents described:

Within three days, we were already in (City X) with the date for the operation. (Int. #1)

Other parents described the slow, incremental build up of concerns about their child that led them to seek medical advice and help. Parents would notice that their child was breastfeeding or eating poorly, walking clumsily, falling down, bruising easily, developing more than the usual infections, dropping things, having concentration difficulties, being ‘slower’ than their brother or sister, and more. They noticed dizzy spells, unusual symptoms and physical signs such as an unusual swelling or
increasing numbers of infections. In short, parents knew that 'something was not right' with their child and now had to convince a doctor or doctors to take these concerns seriously and to prove that they were not simply a ‘neurotic parent’ or ‘hysterical mother’ (Int. #15):

After three months, however, breastfeeding difficulties had resolved, but then he started to become full of mucus. There was one infection after the other. At the age of four months he had his first episode of bronchitis and the first hospitalisation. In his first year, by the time he was one, he had already suffered five bouts of bronchitis. A selective IgA deficiency had been diagnosed. At the age of six months, I noticed that he was lagging behind developmentally. The first paediatrician we saw shrugged this off as him being just a 'late starter'. (Int. #15)

It was Friday night, I looked at his shin and noticed a slight curvature, a bulge. We were watching TV, it was a summer evening, he had shorts on, he climbed on top of me, then I saw something was wrong. I looked closely again to compare the two legs and I saw the whole shin, it was curved. I didn’t like it. Up until then he had never complained of pain. (Int. #4)

Parents often suspected that their child’s condition was serious before any definite medical diagnosis had been made. Parents described this intuitive sense variously as 'just knowing' that something was wrong.

The child’s diagnosis was a ‘passport’ to another country, the land of being the parent of a child with a life-threatening or life-limiting illness. How this diagnosis was conveyed to parents varied dramatically.

The experience of diagnosis

All over Italy and across the world doctors and other health professionals will be ‘breaking bad news’ to parents, patients and families every moment of every day. Parents will be told of their new baby’s serious illness or abnormality while others will learn of the reason for their older child’s difficulties or observed signs and symptoms. Patients will learn of the disappointing results of their ‘tests’ and others will learn that no further curative treatment options are available for their child’s condition.
Given the commonplace and central nature of ‘breaking bad news’ to medical practice, patients and families would be entitled to think that this is something that all doctors would be trained and educated to do well (Barnett, 2002; Charlton, 1996; Daly et al., 2001; Farrell et al., 2001a; Ptacek and Eberhardt, 1996). For some of the parents who took part in our study, this was not the case and their accounts of being given their child’s diagnosis of a life-threatening or life-limiting illness were truly appalling. One doctor recalled clearly that:

I think when you are a medical student it’s difficult because I don’t know if they are talking about this at university. I have done a few courses myself in (City X) I think it’s something that you learn over time. #6

While another noted the absence of this topic in medical education:

The doctor in his career of studies in six years at a faculty of medicine, or during specialisation may not learn this. There is never a course where communicating bad news is taught. (Int. #12)

‘Breaking the news’ sensitively

I must say, the diagnosis was communicated in a pretty good way (Int.#1)

Diagnosis and communication of ‘bad news’ with parents has received considerable attention in the health care literature (see eg: Harrison and Walling, 2010; Kaplan, 2010; Levetown, 2008; Barclay et al., 2007; Mack et al., 2006; Dent and Carey, 2006; Fallowfield and Jenkins, 2004; Hill et al., 2003; Farrell et al., 2001b; Greenberg et al., 1999). Hearing the news that their child has a life-threatening or life-limiting illness is potentially one of the most traumatic and distressing events that a family can experience. For this reason, many of the medical and nursing education programmes described above have focused on how best to convey ‘bad news’ and very serious diagnoses to both children and their parents. Despite the existence of such programmes, it seems that many health professionals receive no education or training in ‘how to break bad news’ and the negative experiences of parents in this study show that the conveying of a bad diagnosis continues to be problematic today.
Parents described how they valued and appreciated honesty and frankness even when the news or diagnosis was bad. Some families were given their child's diagnosis in ways that exemplify best practice. They were told the news in person, the diagnosis was shared sensitively and compassionately, the family were given time to process the information and to ask questions and they were offered immediate help and further support from psychology staff. These families’ experiences exemplified this care:

The diagnosis was clear and both parents were invited to an interview in a room with a psychologist and a paediatrician, who was the head of the department. They tried to explain gently but in reality they didn’t need to say a lot because I knew the diagnosis. (…) I can remember that it was a difficult meeting, shall we say, because of the terrible nature of this diagnosis. (…) But it was good, that there was a psychologist who allowed all of my questions, and the doctor was there (…) There was absolutely no time pressure. (Int. #1)

When we were in (City X) and after they had found the tumour, we were sitting together (…) It was the treating physician, the professor, a psychologist and we as parents (…) They explained to us properly what has been found and what may be possible. (Int. #9)

‘Breaking the news’ insensitively

Sadly, not all parents were treated with such care and sensitivity. As we interviewed some families I listened, almost in disbelief, as parents described being given the diagnosis of their child’s life-threatening or life-limiting illness by telephone late on a Friday afternoon and by email.

This mother described receiving the news of her child’s progressive, degenerative disorder by email:

After DNA diagnostics, it turns out a month later that ‘Maria’ has the disorder and the Father and I are carriers. We were given the news of the diagnosis by e-mail and (…) We have actually had a sleepless weekend and a sleepless year. Because we had no ‘key contact person’ and also because we have no family close by that we can talk to and discuss things with. (…) We looked up Google and I read a lot, and so I’m now aware of what to expect. So now in fact, at night I do not sleep and I cried a lot in the first year. (Int. #2)
These parents were ‘landed with’ the news of their child’s life-threatening or life-limiting illness on a Friday afternoon when there was no opportunity to discuss the diagnosis and its implications, to ask any questions or even simply to have someone to talk to about this shattering news.

Another family learned the diagnosis that their child had a particularly aggressive cancer, again on a Friday afternoon. They were told the diagnosis, the name of the cancer and told to ‘Have a nice weekend’ and that someone would talk to them on Monday:

> It was Friday afternoon on the phone when we learned exactly what the diagnosis was, and the comment was that we should have a nice weekend and on Monday we would meet and talk about the rest. (Int. #4)

Parental reactions to ‘bad news’ about their child’s health are well known and in this respect, the parents of South Tyrol are no different from parents in any other country. Parents will describe how as soon as they heard the words ‘Childhood Cancer’, ‘Tumour’ or ‘Degenerative Disorder’, or when the doctor explained that there is no medical ‘cure’ for their child’s disorder, they enter a state of unreality. They describe ‘shutting down’, being unable to hear anything else that is being said, being in ‘shock’, being in a ‘dream’, dissociating from their bodies and ‘looking at themselves in the room’, and more.

One doctor described ‘learning this lesson’ from a parent and now being careful not to ‘overload’ the parents with information initially:

> A mother once told me, it's like a bomb that explodes in the brain and after that, you understand nothing else, and that has helped me a lot because I do not explain very much at that time, I say the most important things. (Int. #6)

These parents described their reactions following the news of their child’s diagnosis:

> Yes, I mean it is when you hear that, you’re gone anyway, it's like a flash, it's such a state you almost cannot describe. It’s rumbling then the whole time, it’s inside you and churns you up and we understand less and less. After that, the doctors have always been there for us, somewhere. (…)
You understand nothing at all but on the other hand you can hear exactly what is being said. It is like hovering between reality and ‘Hi, what is this place I’m in’? (Int. #9)

I was in the hospital and the doctor simply said to me “Yes, it is a … He then showed me an X-ray and he told me it is a tumour. I felt the ground fall away under my feet, and I was alone with my son until my husband came. (…) But I was totally alone, I was alone. And on Friday I was there in the living room with my child, crying. (Int. #4)

Not knowing. Where there is no diagnosis

There is a particular kind of pain for parents whose child has a life-threatening or life-limiting illness or whose child has died where there has been no definitive diagnosis. This family described the situation of their child who died from an ‘unknown’ disorder:

The first EEG results were ‘highly pathological’, so the diagnosis of ‘late developer’ was superseded and the ‘machinery’ of diagnosis was started. (…)

Yes, the disease still has no name. The geneticists persuaded us to deposit genetic material before his death, so that it would be possible to continue searching for a cause. Both of us (parents) did not really want to do this but the geneticists pressed and urged us to do it on the grounds that we still have two children and they might ask us at some point in the future, maybe when it comes to them having their own children, that it would make sense that they knew the name of the disease. (…) But his death was four years, four and a half years ago, and still there is no diagnosis. (Int. #15)

Parents will often describe how there are ‘worse’ things than a serious diagnosis, for example, not knowing, or even the thoughts and ideas that they may have been fermenting in their minds in the absence of the diagnosis.

“Things are just so unsettling that I think if you have an answer it’s easier to deal with than not knowing.” - Bereaved parent, 2006. cited in (Meert et al., 2008, p.2)
Australian author and doctor, Peter Goldsworthy depicts this phenomenon beautifully in his celebrated novella, ‘Jesus Wants Me For A Sunbeam’ which describes how a family reacts when their young daughter develops leukaemia:

“For Rick and Linda there was also, at the end of that terrible week of waiting and worry, an odd feeling of relief that it had happened to them, and theirs. Anything was better than uncertainty; the waiting had been intolerable, the fear of the unmentionable had almost come to be a desire for the unmentionable; its certainty, its mention, was at least a resolution. To finally hear the word (leukaemia) spoken aloud provided a focus for worry, a definite enemy that they could now face, and fight, together, as a family.” (P. Goldsworthy, Jesus wants me for a Sunbeam. Flamingo, 1999, p.36)

Parents related examples of the best and worst health professional practices in ‘breaking the bad news’ that your child has a life-threatening or life-limiting illness or that curative treatments have not succeeded. They described instances of being told honestly and sensitively, but also of being given inadequate information with inadequate time to process or ‘take this in’. In the worst examples shared, the parents were still angry and hurting many years after this news was given insensitively or even ‘brutally’.

There is much more involved in the breaking of bad news and the giving of a diagnosis than simply giving parents the ‘name’ of their child’s condition and any other facts relevant to it. How this diagnosis is shared will have a profound impact on the trust and respect that parents have not only for that particular doctor or health professional (Barnett, 2002), but for the whole service with which they are associated. A ‘breaking bad news’ that is sensitively and compassionately done can help establish and maintain a trusting relationship between parent and health professional that will help everyone concerned through the difficult journey that lies ahead. A badly and brutally handled ‘telling the parents’ can destroy parental respect and trust not only at that moment but for years to come. One health professional described the process of diagnosis beautifully, when they explained that:
Parents appreciated health professionals who were honest and open with them, but a crucial caveat here is that honesty and frankness are not the same as ‘brutality’ and insensitivity. Such honesty and openness recognises that diagnosis and the imparting of ‘bad news’ is not solely about ‘giving information’, but about the quality of shared humanity between parents and professionals. The information is undoubtedly important, but as parents reported, information on its own means little without the empathetic and respectful discussion of what this information means in the context of this family’s life and the life of their child. Parents valued professionals who worked with them and with their child in a caring alliance.

**Entering ‘the war with the system’: learning to ‘fight for your child’**

Q: It is interesting that you say: fighting for things. Do you have to fight for services or does the health service offer you help?

M: No, never.

P: I am fighting the fight now. (Int. #2)

I was put in a position where I had no choice but to fight ("wage war") against them (the health system). (Int. #9) (This is a parent describing her struggle to take her child home to care for him).

Many families described their relationship with health and social services as a ‘battle’ or a ‘fight’ that was fought over one issue or over a longer period of time. For many families, having a child with a life-threatening or life-limiting illness plunges them into a world of complex, uncoordinated bureaucracies and systems that do not respond to people’s requirements as much as to personal pressure.

In short, these families often learn through their experiences of engaging with ‘the system’ that if they want help, support and care for their child that they will have to ‘fight for this’. Such care will not be routinely described, offered and coordinated for them by health, social and education services, instead they will need to be prepared to ‘do battle’ on behalf of their child.
Parents would describe their disillusionment with ‘the systems’, whether this was health, social services or education. They realised, quickly in many cases, that services would not simply be ‘provided’ or offered and that if they wanted help for their child that they would have to campaign, lobby or otherwise ‘fight for this’.

Facing and fighting the bureaucracy

Here in South Tyrol, it is important to have a trusted contact person because the structures and system are very complex and bureaucratic. (Int. #1)

It is a familiar theme in parents’ accounts in many countries and health systems that ‘the system’ is so bureaucratic that it will hinder rather than support them, that it will be slow and cumbersome, that it will demand constant effort and energy to obtain anything and that it will be frustratingly slow, uncoordinated and complex.

One parent described the situation in South Tyrol as:

Here, everything is so dislocated, so far away, there is no central register of children or families (with her child’s particular condition) and it is impossible to contact any other families. (Int. #19)

Parents in the survey generally felt that ‘the system’ was bureaucratic and made things more difficult for them than they would have wished:
Many parents in this study found similar frustrations in dealing with the systems in South Tyrol. They found it difficult to find coordinated services, to find a key person who could provide clear information, to find and access the person who could make a vital authorisation, to organise effective home care for their child and more. While there may be ‘policies’ or ‘services’ listed ‘on paper’, these may not have worked ‘in practice:

The structures and the positions are actually present ‘on paper’, but in practice it doesn’t work, it just does not. (Int. #1)

When you have questions, maybe at night, or if the child is showing symptoms that you are not sure what they mean, it was difficult to reach someone. So the only way would be to go to the Emergency Dept in (City X). That’s the only way because if you call you will NEVER reach anyone. If you write an email, you will never reach anyone, no one will answer. (Int. #16)

Nationally within Italy, Ugazio (2012) has noted similar organisational problems within paediatric care provision. He cites lack of coordination, limited teamwork and sharing, over-concentration of services in urban centres at the expense of rural communities and the forced and excessive costs of parents having to take their
child to an acute hospital or to a hospital’s Emergency Department because good home care or local health professional advice was not available, for example on a weekend or at night (Ugazio, 2012).

Parents could be frustrated by the difficulties they faced in obtaining the ‘simplest’ of services or items. For one family it was their child’s oxygen mask:

The nasal mask took six months to be approved because the health districts were merged and this Commission, which approves these things do not meet, and have not yet sat down the first time and so on. (Int. #2)

On its own, a struggle to obtain a particular mask may not seem like a ‘big problem’, but for these parents every ‘little thing’ becomes a ‘big issue’ as they accumulate and multiply. As this parent observed:

They look like small things, but when they are all combined, they become huge. (Int. #18)

Parents also described how difficult it could be in accessing financial and other necessary information and support, e.g. the E112 certificate, the European health certificate:

The E112 certificate was a bureaucratic burden, the international health certificate (…) At the beginning we spoke with a secretary, until eventually I reached a department director. Then, I started beating on the table and said, ‘What’s going on here?’ and a few days later, the approval came. (Int. #2)

It is hard to challenge the doctors’ power and networks. When we asked for a second opinion, the treating physician was clearly angry and after they spoke with the Head of Department, the head would not sign the E112 authorisation form. I find it outrageous that they have the power to decide this. Everyone else gets this E112 form authorised. (…) Then as we would have to pay for our child’s surgery ourselves, it costs around 20,000 euros, then my husband said, well a car costs $20,000, you can buy this and that for $20,000, so we should readily spend 20,000 euros for our child. (Int. #16)

A person of trust is already missing. Someone that you can turn to ask questions, even those about school. Also with regard to school, (…) As I have said, is she entitled to have a support teacher? but I didn’t know who to contact to ask. I had
no idea. I had even more questions about the paperwork. What do I need here? What do I need there?

There should also be a contact point or contact office where I can ask all of my questions. What kind of rights do I have? Do I also have rights through my employment? I discovered relatively late that I could get three half days per year off, but this is stuff no one tells you. (…)

I knew someone who now lives in (City X), who has a severely handicapped girl and she told me that she has, she quit her job to care for her and she lost this right, but she should have receive two years paid leave and she didn’t know this. No doctors have ever told me and no one helps you in these matters.

Also from the paperwork side, you always have questions, about what you are entitled to and what you are not. Even when we needed to go to (City X) in (country Y) I had no idea what I needed to do. (…)

Then the doctor in (City X) told me I needed the E112, which is a special form. Oh! I said, So I tried to find out about this and who I needed to ask. But who do I ask? I had to ask the Chief Physician of the Paediatric Department, but who do I ask there? Nobody? And that is a pity. You have enough work to do looking after your child but then you have to find out everything for yourself, criss-crossing ‘every which way’ and that takes a lot of time. (Int. #16)

For some parents, their frustration with ‘the system’ was the lack of coordination between people, departments and services:

We actually had to organize everything on our own, because the woman at the hospital in (City Y) in (Country Y) who was supposed to do this work for the parents said that she wouldn’t be able to help because she is not getting anywhere, not getting anything at all, because she’s always hitting a brick wall. It’s just that nothing happens. (Int. #13)

… I’m just sorry that there is no cooperation. (…) Either you do what they want or you have to look for someone else, but you cannot talk about such things. (…) My child’s condition is a complex disease, affecting the bladder, the head, the back, the feet, then you need to go to orthopaedic surgeons, they often have scoliosis or so, it needs many doctors and if there is no proper leadership, then you go to this person and then that person (…) Everyone treats their own little part, there is no group or community. (Int. #16)

For parents to feel that they must ‘fight for their child’ is a difficult position to be in because they cannot afford to alienate health services or influential health
professionals, lest this should impact on their child. But parents will quickly become 'like lions' in defense of their child and in 'getting the best' for them from the health and support systems. As this parent explained about trying to find out why her child had not been given a specific as opposed to a 'general' medication which was accepted ‘best practice’ for her child’s condition:

Moral of the story I wanted to get to the bottom of it, because you have to be stubborn in some things. They can hurt me, but if they touch my children… (Int. #18)

Parents described having to continually advocate for their child, especially to access services or to have their issues or concerns about the child’s condition listened to and then addressed. Some parents described dismissive if not hostile attitudes of health professionals and services if they were thought to be too ‘pushy’ or demanding, or if they dared to question health professionals, perhaps by asking for a ‘second opinion’. Parents described how they needed to become a ‘different person’, whereby they had to adopt attitudes and approaches to dealing with health professionals and services that were new and even uncomfortable for them. A fairly typical account here was that a parent was a fairly easy-going person who believed in asking politely, being patient and respecting the professionals who were the experts in the field. However their often bitter experience may have led them to an understanding that the only successful approach to gaining help and service provision for their child and family is to ‘fight for everything’. If this came with the attendant risk of being labelled as a ‘pushy parent’, then this was simply the price to be paid for advocacy.

Some parents in this study identified exactly the same problems as Ugazio above. (Ugazio, 2012). The care of children with a life-threatening or life-limiting illness should never be a primarily economic concern, but there are economic questions at play here. It is neither a good use of parents’ time, nor of health service resources for them to have to rush their child to an Emergency Department when the correct advice or care could have been given locally. It is neither desirable, nor economically sensible for a child to be cared for in an acute medical ward or ICU when he could be cared for by his parents at home with support. In considering end-of-life care for children, it is also rare that parents will want their child’s last
days to be spent wired up to the technology of a busy ICU when they could be at home in the arms of their parents and in the bosom of their family. Where studies have considered the economics of paediatric palliative care in the community, they have shown that this is not only the more humane option but the most cost-effective (Rogers et al., 2011; Pascuet et al., 2010). For example, a study from the USA showed not only improved quality of life and reduced hospitalisation by one third, but an approximate 11% cost saving (Gans et al., 2012).

The health professionals' perspectives of ‘the system’

In interviews and in survey comments, many health professionals agreed with the parents who found ‘the system’ of health care to be complex and bureaucratic.

One health professional commented that:

How good is the system? Currently it is weak, I would venture to say (...) and certainly the bureaucracy, because everything is very slow. (Int. #5)

However, there was an interesting contrast in the health professionals’ survey responses. When asked whether parents found it easy or difficult to ‘navigate the system’ to obtain services for their child, most health professionals thought that ‘the system was reasonable’:
However, when asked if health professionals found it easy or difficult to access services and support for families, a large majority thought that ‘the system is complex and bureaucratic’:

<table>
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<th>D8HT:Q21 - Does ‘the system’ in South Tyrol make it easy or difficult for professionals to obtain such services and facilities for these families? (N=27)</th>
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<tbody>
<tr>
<td>The system is complex and bureaucratic and makes this very difficult for staff</td>
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<tr>
<td>The system is reasonable. Staff can find help for these families reasonably easily</td>
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<tr>
<td>The system is very user-friendly and responsive for the staff who are helping those families</td>
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Perhaps as health professionals based largely in hospitals, the respondents may not appreciate the difficulties that families experience as acutely as they do their own struggles with ‘the system’.

**Fighting the services from within**

Parents in hospital or at a clinic with their child often felt ‘at odds’ with the health professionals caring for their child. Parents may have started by being grateful to staff and deferential to their ‘greater expertise’, despite the quality of any service received. As these parents stated:

> It varies depending on the health status of the child. On the other hand you have to be happy that you even get a support. (Survey)

This more ‘accepting’ view often changed when parents felt that they had to ‘take a stand’ for their child, even if this risked making them unpopular.

For example, disagreeing with staff is very difficult for a parent as staff are perceived to be ‘the experts’ in children’s health, especially in a hospital setting.
(Darbyshire, 1994) and even more so in a specialist Intensive Care Unit (ICU). This parent echoed the experience of many other parents worldwide when she described how her understanding of her child and their abilities and understandings while the child was ‘in a coma’ differed from that of the nursing and medical staff:

The only occasion where I "have been at war" was just in the ICU when they always said he does not feel anything, he hears nothing, he doesn't understand anything and they tried to get me to agree but I was convinced of the contrary and I always defended myself vehemently. (Int. #9)

While parents may lack the legitimacy and power of professional nursing and medical knowledge when they are in the ‘home ground’ of the child health experts, they are adamant that they possess an equally valuable kind of ‘expertise’ that comes from their profound knowledge of and relationship with their child:

But after three weeks there, (in hospital) we could stay with him as long as we wanted, we were allowed to sit with him from eleven clock in the morning until eleven at night. We either rotated our visits or came together for the three weeks. (…) We have had to really argue and fight tooth and nail with the doctors for weeks. (Int. #4)

As Darbyshire (1994) has explained:

“It is possible that in situations such as this where the child's medical condition was the prime focus of professional attention, that parental knowledge was seen to be at its least reliable and relevant. The parent was in the position of trying to participate in an arena of discourse where professional knowledge and professional language were the accepted currency”.
(Darbyshire, 1994)

One parent’s account of their harrowing experiences in a hospital ICU illustrated the powerlessness that even ‘knowledgeable’ parents experience when confronted by a ‘system’ that dismisses their relationship with their child and their knowledge of their child.

In a lengthy description, this parent told us of their child's surgery for a major tumour and their subsequent recovery in an ICU in Italy. In this paediatric ICU the
'policy’ was that parents could not sit with their child during post-operative recovery and as a result, the parents were kept in an adjoining room where they could hear their child’s crying and distress growing but were prevented from comforting them. Despite the parents’ pleas (and both parents were experienced health professionals) to be allowed to sit beside and comfort their child, they were denied. Eventually the child became so distressed and their “crying and raging” (Int. #1) so pronounced that their suture line ruptured.

Given these parents’ experiences it is unsurprising that many parents experience not simply ‘a bad time’, but clinically significant post-traumatic shock following their child’s ICU admission (Colville, 2012):

One of the most dramatic things that happened was right at the beginning when he was operated on in (City X) and that is one of the most horrible things that we have experienced. It was when he woke up from the anaesthesia, we were not allowed into the intensive care unit and I spent all night at the door of the ICU and heard my child screaming inside, an intubated scream and I spoke with the doctor and I have talked with the nurse to ask if could not go in, because you have to understand, he was only a toddler. (…)

He was conscious and awake when he went into theatre and then he woke up from the anaesthesia and was in a totally strange environment with the hose, the ventilation tube inside his throat. There was also the problem that they only spoke Italian and he only understood German. I tried to explain this to them, I tried and begged them all night and I showed them my (health profession registration card), I told them I know my way around, I have worked in theatre, I have worked in Emergency, I know how you should behave. I will behave quite factually not emotionally, I just want to go in to comfort and calm him, to act as his interpreter when he says something. Eventually they let me in. That was also a big problem postoperatively, in that he had cried so much and increased the intracranial pressure that the wound split open, so there were complications and that was really bad.

I was feeling really desperate, because, at the beginning, the hospital staff, doctors and nurses, but especially the doctors in (City X’s) intensive care unit, thought I understood only German and then I have heard comments that they have made in Italian, the reasons why they didn’t feel like doing anything, and I have to wait outside getting to the point of despair. I could have killed them!

I: What was the reason?. Why were you not allowed in?
P: The reason was only that no parents or ‘external people’ were allowed in the ICU (Int. #1).

It is hard to imagine a situation, deliberately created by health professionals and their ‘policies’, that is more guaranteed to inflame and antagonise parents to the point where their fundamental orientation towards a hospital or health service will be one of distrust and antipathy. The additional fact this was a paediatric ICU that should have a special responsibility for the family centred care of children and parents makes this parent’s account even more shocking:

Since you have to say that this was a children's ward where really there were only small children but the main reason I believe that I was driven to such despair was that the doctor on duty that night, did not feel like somehow, speaking with us and would not let us in to the unit to be with our child (…) It was, the surgeon whom I knew well who talked with us after the operation, we had a conversation, and he said that it is important to calm the child, it is important that ‘Mario’ remains quiet, even if we need to use medications, but the child was crying and raging all night. (Int. #1)

As the above parent noted:

If we had known beforehand (that we could not stay with our child), we would never have gone to (City X). (Int. #1)

The comments of international hospital safety expert Don Berwick are most fitting here. Berwick also tried to accompany an adult friend during a diagnostic procedure in hospital and was ‘forbidden’. Berwick highlights exactly what is wrong with this kind of professional imperialism:

“\textit{What is wrong is that the system exerted its power over reason, respect, and even logic in order to serve its own needs, not the patient’s. What is wrong was the exercise of a form of violence and tolerance for untruth, and} — \textit{worse for a profession dedicated to healing}—\textit{needless harm.}"

\textit{The violence lies in the forced separation of an adult from a loved companion. The untruth lies in the appeal to nonexistent rules, the statement of opinion as fact, and the false claim of professional helplessness: “impossibility.” The harm lies in}
increasing fear when fear could have been assuaged with a single word: ‘Yes.’”. (Berwick, 2009, p.555-556)

Fighting for services at home

It is an omnipresent theme running through parents’ accounts across the world, that services for seriously ill or disabled children are very rarely freely offered, readily available and accessible and co-ordinated in ways that make parents’ lives with their child easier (Kluth et al., 2007; Ryan and Cole, 2009; Baruch, 1981). Research and government reports over the last 50 years have highlighted how difficult it can be for families to obtain services for their child.

Parents in Canada have described how:

“We’ve been fighting everything out there for so long and so many years, that it’s like, I’m just tired of fighting the system”. (Darrah et al., 2002, p.545)

In England, a mother says:

“It’s just that everything is a fight, which it shouldn’t be. It’s hard enough having somebody who’s got a life-limiting disability and like we’ve said I go to bed tonight, I don’t know if she’s going to wake up in the morning. You have that, yet everything else which you shouldn’t have to be worrying about, you still have to fight for”. (Wood et al., 2010, p.802)

In Scotland, researchers similarly report:

“A theme that emerged strongly was ‘fighting the system’ primarily for educational support but also for therapy resources”. (Stephenson and Chesson, 2008, p.341)

Even in Norway, which has one of the world’s most admired health and social services, researchers found that:

“The “fight against the system” seemed to be the most problematic issue”. (Dybwik et al., 2011)
Families in South Tyrol reported similar problems and obstacles as they also sought to find and provide the care that their child with a life-threatening or life-limiting illness required:

She (the service manager) has also fought, I think - to get four or five hours of nursing service for us. So we got five hours of nursing from the Community Service in (City X). (…) I really fight for everything that is being offered. (Int. #13)

Families’ difficulties were described in relation to a wide range of problems and services such as: finding knowledgeable and skilled health professionals to help, finding accurate information, obtaining supplies of specialist medical equipment and medications, learning the ‘technical aspects’ of the child’s care, making the transition to caring for the child at home, modifying the home to suit the child’s care needs, having the home become ‘a hospital’, managing other children in the family, juggling work and other family commitments, trying to understand and access financial and other entitlements (such as the E112 certificate) and much more.

**Being ‘in the dark’: uncertainty and information**

We met many parents in (City X) who were either in the same situation or in a similar situation, and who were not so well informed as we were, they were much more left in the dark and so they did what they were told. (Int. #1)

To better understand their own situation and the nature and implications of the child's illness or condition, parents require information. They need information about the ‘practicalities’ of living with and caring for a child with a life-threatening or life-limiting illness, the treatments and procedures that will need to be undertaken and what the prognosis will be for both the child and the family.

**Being in the dark and uncertainty**

Finding out accurate and understandable information was felt to be crucially important because ‘being in the dark’ and the uncertainty experienced by parents were very stressful and impaired the parents' abilities to function effectively as the child's carer and as the person that was seen by the rest of the family as being the obvious source of expertise and information regarding ‘what was going on’. The
uncertainty that was experienced related most often to the child's treatment and prognosis and to the lack of information that parents were given.

Uncertainty hampered parents’ ability to participate as effectively as they wished in their child's care, as they felt unable to make the appropriate contribution to their child's care, being unsure about what this might be.

Parents often ascribed such uncertainty, not to the fact that doctors and nurses were themselves genuinely unsure and uncertain but that they were not being honest or open in sharing knowledge and information.

Several parents described having to constantly ask for information and updates on their child's condition:

Every day for three weeks (in hospital) I tried to talk with at least one, if not with two senior physicians. Day in, day out. Not occasionally, but every single day of these three weeks I asked the doctors how does it look? what do you mean? how is the situation? what do you think? They should be honest with me, they should tell me what chance he has, how bad or good does it look. (Int. #4)

This parent recalled being ‘avoided’ by their child's doctors:

One has to say when the tumour's recurrence was clear we were totally ignored in (City X), totally ignored. I really wanted to talk to the doctor who had been in charge of ‘Mario’ for about a year. (…) I wanted to talk to him, and then I have, tried for, yes, ten days I spent trying to reach him and I was always rejected using whatever excuses somehow. (Int. #1)

Another parent managed to secure a meeting with her child's surgeon, only for the surgeon to take calls on their mobile phone throughout their ‘conversation’:

We had a conversation with the surgeon who did his operation, we sat there and the conversation lasted three quarters of an hour. His mobile phone rang again and again and he answered it. Even a senior colleague made a comment about how stupid this was and that he should switch off his phone. (Int. #4)

Eventually, parents will be ‘pushed’ from a position of deference and passivity in the face of professional power to adopt a more forceful advocacy role whereby they
recognise and insist on the recognition of their own expertise with their child. As this mother described:

But I recognIse this, that the information was not given to me and so I get up very quickly and very loud and since they recognise, that I really know what I am saying and I know what I am doing, they respected me (...) as a mother and as a nurse, as a person who works in medical fields and since then it got better in (City X) but not here, not here in South Tyrol. (Int. #2)

Parents shared with us their experiences of finding helpful information about both their child’s life-threatening or life-limiting illness and all aspects of their treatment and care, including, where relevant, the period of palliation. Information is clearly a very broad area and, not surprisingly, parents described a wide range of perceptions and experiences here, from great satisfaction with health professionals and services to marked anger and frustration.

The types of information that parents sought and required was similarly broad. Parents needed clinical information about the child’s illness or condition in a form and at a level that they could understand and which did not ‘baffle them with science’. They also needed practical information about the implications of the child’s illness. In everyday terms, they needed information that would answer their many questions such as:

- What does this illness mean for my child and our family and our everyday lives?
- What will my child be able to do or unable to do?
- What special equipment, facilities, medications or other treatments will be needed and where will these come from?
- What will I do if need something at night or at the weekend?
- What are the financial implications of my child’s life-threatening or life-limiting illness and care?
- What help is available for our family?
- How should we talk about this with our other children?
- Who should we contact about this?
- Who will be available to help us at this time and what will they do?
- What about our child’s friends, schooling and social life? and
What kinds of activities will our child be able to participate in and to what extent?

The last and most difficult questions for parents to even think about, let alone ask, were those about the last stages of their child’s life when they knew that recovery was no longer possible - questions such as:

- What will this be like for our child?
- How will we know that death is imminent. What does it ‘look like’?
- How will we recognise it when it happens? and
- What do we do then?

This is not an exhaustive list, as parents, families and the child or young person themselves often have many more questions that require skilled, knowledgeable, sensitive help to answer.

The making and breaking of trust

In part, the problem is global, in nursing family care and that I see in our work, those concerned, whether the children or adults, need a trusted person (Int. #1)

If we accept the vital role of a trusting relationship (Bova et al., 2012) between parents and families and their health professionals and health services, then the accounts and perceptions of the parents in this study are valuable and illustrative of how such trust can be both established and strengthened or absent and destroyed.

It is very difficult for parents, especially in the early stages of realisation that their child has a life-threatening or life-limiting illness, to ‘know what they don’t know and what they need to know’. It is even difficult to know what questions to ask. As one doctor observed:

Parents who are not nurses themselves often don’t know what is lying ahead of them. (…) They would prefer to have the child at home because most of them have families and other children, but, really, but if they are not nurses they can be overwhelmed. (Int. #11)
This is where having a trusting relationship with health professionals becomes so crucial.

In the survey responses, most parents described having complete trust and confidence in the health professionals caring for their child:

Creating a trusting relationship

Parents valued and appreciated health professionals who were open, honest, caring, compassionate and clearly competent and who demonstrated these qualities in the care of their child and in their dealings with the parents and family. One parent encapsulated all of this complexity in a phrase when she described her physician:

She was a human doctor. (Int. #18)

Other parents also identified this essential ‘honesty and humanity’ (Int. #4) as something that engendered trust and a good relationship between them and their health professionals. Another parent’s account highlighted the importance of this ‘human’ quality in enabling health professionals to work with and within a family and in a family’s home where ‘the rules’ are so different from those in a hospital:
The first thing is to be human, don’t just follow the paragraphs of the rules, because in the hospital situation, there are different rules, but the situation at home is something quite different. There is a child, there is a family, there are siblings, there is the whole ambience. There are certain things you cannot organise as if they were dictated by the hospital rules and so it simply needs more flexibility. What I feel is very important for me is to have confidence and trust in the person who is next to my child. (Int. #9)

Parents in our Survey also highlighted the importance of humanity and compassion in services when we asked them to suggest palliative or supportive programmes that were not available in South Tyrol but that should be. They wanted:

- Human, compassionate, competent medical assistance, eg trained palliative physicians, more home care services. (Survey)

Similarly, when we asked parents to list the most important qualities of staff who care for them and their child, a survey parent answered simply with umanità - ‘Humanity’.

Finding someone ‘special’

As parents spoke about their journey through the health care and other ‘systems’ with their child they often spoke of finding a ‘special’ nurse, doctor or other person with whom they established a trusting relationship that was invaluable in helping them care for their child. While it was good to hear accounts of such success for the individual families, it raises the question - ‘Why should this be a matter of ‘luck’? and why are all health professionals that families encounter not ‘special’?''

Parents of a child with a rare degenerative disorder spoke glowingly of their ‘special’ doctor who was closely involved with the Parent Support group for that particular condition. This was a doctor described by parents as “Our own Dr.X”:

- We have our own (Dr.X) for these things. (…) Because now Dr. X took so much to heart this group of (children with X) and is thus so involved both in the Parents Association and in therapy, she is like a sponge, soaking up information and ideas for us. (Int. #19)
One family who were both health professionals themselves were, at points, able to use their connections, colleagues and network within health services to help them:

It was simpler because you know a lot of doctors in the hospital and you can ask them questions in the days after about this diagnosis that you have received. (…) I contacted Dr. X., he was also a personal friend of mine and he then established contact with Dr. Y, who had a very senior position at the Health Department (Int. #1)

Another mother described managing to find a pain specialist who came to see her child as ‘a favour’:

The pain specialist at (Hospital X) was a friend of Doctor ‘X’ and she (the specialist) did us a favour by coming to our home. (Int. #15).

Another parent described the ‘human’ doctor who had been so important in her and her child’s life:

Since that time, Dr. X has had a special place in my heart, she was a human doctor, yes, one that goes above and beyond. (Int. #18)

While for this parent, it was the ‘special’ children’s nurses in a hospital who had been so helpful to them:

So what was pretty good here was the nursing service in (City X). The nurses seemed very competent and knew what to do in our particular situation. They found a special children's nurse just for us and with these two who were mainly working with us and two other nurses who were really familiar with our needs and were really a big help for us. So then we were able to just go out, get normal things done, go shopping, even go down to the basement in our house which wasn’t possible before. (Int. #13)

This parent echoed the experiences of others as she described the social service she used and how a relationship of trust based on open, responsive communication and information, flexibility, respect for her as a parent, had been built that was “everything she needed” in helping her care for her child:

We had everything. As I said we had arranged everything with the Community Services, everything we needed, even the flexible schedule, and I have to say they then organised everything for us and when it was no longer needed it, we stayed in contact by phone. After his last hospitalisation in Autumn, they came
immediately and organised everything once again just as before. Even on ‘Mario’s’ last day they came and everything functioned well.

(…) They came to the hospital to learn all of the little details that they needed to help care for ‘Mario’ at home and saw what it takes and what would be necessary to organise, and therefore from the beginning, she was always there, it was the Nurse Leader of the group, let’s say, but she was the person who truly trusted me wholeheartedly. (…) She said, I’m here if you need me, she gave me complete confidence in every respect. (Int. #9)

For other parents, finding a ‘special’ health professional or service meant ‘moving outside’ of the mainstream health services. One family, using the Internet, found an independent health professional in another region who had specialist interest and experience in their child’s very rare degenerative condition:

My wife, then searched the internet again and we found Mrs. X and a Swiss family in an (Child’s illness) forum. My wife got the phone number and the address of this woman Mrs X in (City X). I then emailed this woman, the same evening (…) And she called me the next day, was the Sunday night. (…) For over twenty years, she has cared for (Illness X) families and children, almost alone. (…) So the parents go there, and after two days of doing the course they go home with all the equipment and training.

The parents know what to do in case of an emergency, in case of aspiration, in the case of a fever. (…) She is independent of the health system and does this all by herself. She teaches the parents to do this on their own, because she also knows that in the regions and in the health districts of Italy there is no support. She does this in such a way that enables the parents to be the experts. (Int. #2)

For parents to trust a health professional or service they need that person or service to appreciate and understand that they are not simply a ‘case’ or a collection of ‘technical tasks’ to be accomplished, but a real family and a real child. One mother described a trusted health professional as:

The one who sees the child as a whole and not only organ-related. (Survey)

and a health professional agreed:

Yes, and it is also a problem that the patient is not seen as a whole, everyone sees only his part. (Int. #5)
This professional and human ability is vital to parents and cannot be overestimated. This mother explained how she herself wanted nurses to ‘see the child’ behind her son’s illness:

Put away the fear and uncertainty because you cannot go wrong, if you follow your gut feeling and instincts. In any case, you need to look at the patient, so you need to look him in the eyes, and look and do not just think of ‘what do I have to do now’? You have to watch him and see, and then you will know what is good and what is not good. (Int. #9)

These parents described this vividly as they explained what makes a health professional or any other ‘helper’ in their child’s life valued:

I think if you want to help the children and the families, I think you have to take the time. A lot of empathy is required and I think it needs people who can be trusted. I trust people, where I feel they really want to know how we are doing and not people who just come in and look at the ventilator. So, I watch who is watching ‘Maria’, I watch for who looks into ‘Maria’s’ eyes, or mine. That's very, very important, that's how I know. (…) So if I sit with a person who says she is in a palliative care team, I can judge very quickly whether she is really interested in it and does she have the experience or not, for example. These are things that I pick up very quickly and they make a huge difference to me. (Int. #2)

The breakdown and betrayal of trust

They (doctors) are cold and inhuman. (Int. #4)

In stark and sad contrast to the parents’ accounts of their positive relationships with health professionals and services were the experiences of parents whose encounters with health professionals had created anger, resentment, and distrust.

Parents cited numerous factors and reasons for this breakdown or:

…breach of confidence. (Int. #1)

such as, health professionals who were seen as dishonest, dismissive, uncooperative, uncollaborative, arrogant, uncaring, unsupportive, inaccessible, incompetent and more.
These parents’ accounts exemplify such breakdowns:

In (City X) we had quite a few bad experiences and we wanted to discuss them with the medical director but we never got an appointment and then the ‘Citizen’s Affairs’ office told us we had to submit a written complaint (...) because when the tumour’s recurrence was clear, we were totally ignored in (City X), totally ignored. (Int. #1)

This parent also described an ‘incident’ where they had to argue with medical and nursing staff about an error in the administration of their child’s medication:

The nurses said that the medication was prescribed by the doctor and so they gave it. When I came the next day and looked for the doctor to ask why he had been given this medication, at first everything was denied. Then, the next day, the doctor showed me his drug chart and I saw that it had been corrected retrospectively and another new medication prescribed. (Int. #1)

Later in this family’s journey with their child it became clear that their child was dying and they wished to care for ‘Mario’ at home. The initial response of their medical specialists was to threaten them with legal action:

We wanted to take him home but they wouldn’t let us because the doctors from the clinic said that we wouldn’t be able to care for him at home and that it would be a big drama to do this. At first, from the medical side we were threatened with police action if we were to take him home and that was a huge worry for us, a huge worry, because we couldn’t tell if we would get sued later. (Int. #1)

Another family described a range of negative experiences with some hospitals and health professionals that had colored their entire view of medicine and health services:

So the senior physicians out there are on a different plane and a higher level than all the rest, and they have a certain coldness that I can understand very well (...) But still they should have a bit more humanity, I’ve really missed that. (...)

Then I drew the nurse’s attention to it (a problem with her child), but she just laughed at me. I insisted and pressed the nurse three times to call the paediatric surgeon (...) they laughed at me and said it’s fine, we don’t need to do this. Honestly, because the doctors, they’re just not being honest. They are just not being honest and even when they saw the MRI and then the … then I have to say it again now, they are just not honest. (…)

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What help? Why does our child have to go through this? Who is all of this for? It's not about children, it's the worst. It's all about a piece of paper. (Crying) And doctors are not honest and are not open and are not human and are not respectful. (…) 

So every day a top doctor comes to do their rounds, and as there are four of them, every day is a different doctor and there’s always another one (…) (…) and they’re not open, they are not open and not honest (…) they have known that they have lied.

I have to say again, from my perspective, (Mr X, a psychologist) I hope I never see him again in my life. (Int. #4)

At the heart of such angry disillusionment with health professionals and the health system is the parents' belief, based on their experiences, that their child was not seen first and foremost as a child, but was objectified into a collection of signs, symptoms and results:

(Crying) Why do you have to put the kids and everyone through hell. I told them (the doctors) there is no ethics, there is no dignity, there is nothing. And ‘Mario’ has suffered so much, he has had such pain with all the viruses and everything. They have seen it but they have come in and have said that the blood test results are good, so the paper is good, but nobody looked at the child in the bed, but I have looked at him. That is what treatment is like today. (Int. #4)

Similarly, another parent described the ‘very bad first impressions’ of meeting a genetic specialist where, after ‘walking around the child with a tape-measure’ and remarking on ‘Mario’s’ various facial features, he began dictating the assessment notes to the secretary without realising that the parent understood Italian. As the parent listened, they realised that his assessment seemed to bear no resemblance to their child:

Nothing at all that he was saying matched my child in any way. (Int. #15)

This same parent, who is also a health professional, recalled another incident that shook her confidence in a particular hospital. She watched, horrified, as a nurse attended to a central venous line that had disconnected, by picking the line up from the floor and reconnecting it. As the parent explained:

I would not have left my child alone in that place for five seconds. (Int. #15)
Another family with a technology-dependent child will not go back to a particular hospital:

P1: We have never been in the hospital again, except in the emergency room (P2: never again), and never again. (Int. #2)

While another family reported being effectively ‘punished’ and ignored by their medical specialist for not following their advice:

So my paediatrician is not a reference.
I was always in ‘X’. and was always very happy. But when you have so many questions has, maybe over night, or if my child had a complaints and where I did not know what it was, it was really difficult to reach someone. (…) That's the one, because if you call by phone, they are never reached. When you write e-mail, they never reach, no one replies.
Can I can speak with Dr. ‘X’? No it is in session. When should I call? In an hour. Now she is gone. So unreachable.
And I find that very sad, now I'm lucky, I have a friend who is a paediatrician who is now in the intensive care unit in X’, she has done the training and now she's in ‘X’. and she is my contact person. Just someone where you can call and they really do get back to you.
The neurologist replied after two days to my emails but now they are so upset with me because I did not do the things they said, and since then I have not heard from them. Since July. I miss them. (Int. #16)

Parents expect to be listened to and to have their concerns and views respected rather than to be patronised, deceived, threatened or ignored. As one health professional commented,

To say how are you, are you all right ma'am?, really does not take much. (Int. #7)

They expect a genuine dialogue and partnership with their health professionals based on honesty and openness, tempered with tact and sensitivity. They also expect that their child will be treated with a similar respect. If parents do not find such help in one setting or hospital, they will naturally look elsewhere.
Finding ‘the best’ for your child:

Most parents were not aware of the existence of a paediatric palliative care service and had not been offered such specialist support:

![Bar chart showing responses to a question about receiving help or support from a children’s Palliative Care service.

The travel for treatment

In almost all of the parents’ accounts of their child’s illness and treatment journey there were discussions of the many places and services that parents accessed.

Families described going to (or having to go to) a wide range of centres in Northern Italy, Austria, South Germany and elsewhere.

For some families, language was a consideration as they wanted to be in a predominantly German or Italian speaking centre:

I just felt like it's a natural tendency to go to a German speaking centre. That was my feeling. (Int. #4)

Also because the families who speak German mostly, because we also have this problem with language here, they go to (City X), almost all of them. Those who are native Italian speakers go to centres Y or Z in North Italy. (Int. #18)
But still we need to go to Germany just because of the language. (Int. #2)

For most though, the move outside of South Tyrol was to access a particular specialist service or expertise that was not available in South Tyrol because:

...they are not organised for such diseases. (Int. #2)

or because of what one health professional called ‘the missing experts’:

There is no physician specialised in paediatric palliative care. (...) The ones who are specialised are not really accessible, they even don’t have the right specialisation so you can’t really ask them, so you have to turn to specialists abroad and in other parts of Italy. (Int. #11)

or because they had lost faith in the existing South Tyrol services, hospitals and departments.

Many parents described such ‘having to travel for treatment’:

Since 2004, we have completely stopped going to Hospital in (City X), we found a treatment centre in Northern Italy which has now become a support Centre for (child’s illness) because otherwise it would have meant going to (City Y), where we found a team that is wonderful. Going there is like going home, we have such a good relationship with the team there, that travelling isn’t a problem. (Int. #18)

We were in Hospital X, in (City X), in (City X) a lot, and then I got a second opinion, from (City Y) and from (City Z). (Int. #1)

Asking for a second opinion

In trying to do the best for their child parents were in the difficult position of ‘not knowing what they did not know’. As one mother tried to explain:

In (Hospital X) I must say you could ask questions, but in the end what should you ask? Because you don’t understand anything, at this time, you don’t understand what's going on. (Int. #9)
When parents first realised that their child had a life-threatening or life-limiting illness this raised a multitude of questions about the child’s treatment, prognosis, care, management and numerous other questions.

In today’s era of Internet access with its almost unlimited access to information, examples from other families and treatment centres, parents will inevitably have more questions and will be able to use the Internet to find out about and judge the quality and adequacy of information and advice that they receive.

In many cases, parents will want to check or satisfy themselves that they are receiving the best advice and to check on what other options may be available to them. In brief, parents will ‘ask around’ and will ask for ‘second opinions’.

In a quality children’s service that is confident about the treatment, advice and services that it provides, this will not be ‘a problem’ and indeed they may well suggest that parents ‘ask around’ to satisfy themselves that they are making the correct choices and may also refer them to other expert sources.

Unfortunately, we heard accounts suggesting that such professional openness and collaboration were not the ‘norm’ in some places in South Tyrol:

The big problem is that (Hospital X) doctors have great difficulty in consulting or discussing with other doctors. (Int. #18)

There are people with whom it is easy to collaborate, but there are also other ones. (Int. #11)

Open and collaborative suggestions about a second opinion or medical support for parents to ‘ask around’ if they wished rarely if ever happened to the parents in this study. What was more commonly reported was that a request for a second opinion was met with defensiveness and pique from medical staff who felt that such a request was a slight on their expertise.

These parents struggled to understand why their request for an additional medical opinion was met with such resistance from their doctor who:
They believed that it was essentially, ‘professional jealousy’ or arrogance:

From my point of view, it's jealousy.

I had the feeling they are jealous that you have asked another doctor for their opinion. I never said that she is a bad doctor, never, I've written, I was always grateful for what she did and I was always happy with it. But you should be able to ask for a second opinion. But they're jealous that maybe someone else could do it better. I do not understand ... I myself, don't understand why they are against it. I always try to get a second opinion about anything, even small things. (...) But our child's operation was a big one and is not a small thing. (…)

When I asked the chief physician who had never seen ‘Maria’ before and who didn't even ask to see her, it was ‘No’, she only replied that the girl doesn't need an operation. ‘But you have never seen her’, I told her. This decision was made by a neurologist, that there was nothing to do. I was always satisfied with everything in (Hospital X), with all the physical therapy, the doctors, the paediatricians but after how it went last year, I find it really a shame. (Int. #16)

Not in (City X), but also within the (Hospital X). When I go there I feel that people are looking down their noses at me. They say there is no need for me to ask others for an opinion. He was so very full of himself.(Int. #18)

And the doctors out there even denied that they have ever heard of (Institute X) in (City X), the orthopaedic clinic, which is a world leader in the treatment of (child’s illness). We now know, that is a world leader, not just a centre but a world leader. (...) So a South Tyrollean doctor has said that they have never heard of the (Institute X) in (City X). (Int. #4)

One family mentioned a particular difficulty they experienced in asking for a second opinion and a referral to another centre of expertise, and that was that their child had been enrolled in a clinical trial in that centre and the doctors were reluctant to have them 'move' to another centre.

Bypassing ‘the system’

When parents found that they could not manage their child's care as they would wish using South Tyrol’s existing health professionals and services, their other
option became to ‘by-pass’ the system and to access services either elsewhere within Italy or in another country or outside of the ‘formal’ health system:

With this illness, all children are not the same and it is so complex that one person cannot understand it all or do everything. So doctors need to cooperate and talk with others. That is why we stopped going to (Hospital X). (Int. #18)

Another family resorted to ‘homeopathic’ compounds that they sourced ‘by mail’ (Int. #9).

In addition to the independent health professional mentioned earlier, one family described how they ‘by-passed’ systems and places that were of no help to them and instead established their own ‘trusted network’ of professionals and support:

We have never been in that hospital, except in the emergency room (M: never again), and never again.

They are simply not equipped, let alone to care for ventilated children. They would send us to (City X) or sent us even further. (…)

If we have a problem, we do not call here at the hospital, but we call on either XY, we have found a contact person (M: I found a girlfriend).

Meanwhile, she has become a friend, but she is also a palliative paediatrician. And she supports us by phone, if need be, any time of day or night.

Otherwise we'll call (City X) with this woman Mrs X, then we can really get some very practical tips and so on. So these are our key contact people, here in South Tyrol specifically for this condition. No, we don't have any contacts.

The paediatrician comes to us, OK, that fits, but everything else we do separately from the health care system, simply because it does not work, they cannot give us that. (Int. #2)

**This is our life: the battle against the illness**

If ‘fighting for their child’ was a common theme in parents’ accounts, then an equally present theme was ‘fighting their child’s illness’. Parents accounts were replete with the details of the countless ways in which they were continually fighting to keep their child as happy, healthy and ‘well’ as possible within the limitations of their illness or condition.
The parents as nurses

Simply reading the parents’ stories was exhausting, such was the scale of their efforts in caring for these children and a research report such as this can scarcely do them justice. This was often 24 hour care and monitoring of a child in the family home while also trying to ‘juggle’ and balance all other aspects of family and life, such as other children, possible work, spousal relationships and more.

One set of parents’ account of providing palliative care for their seriously ill child at home is illustrative:

So the days pass so that we take turns the two of us, once again, she stays with him one night, a night I will stay with him. He sleeps in the living room. Whoever stays with him sleeps next to him on the sofa. He needs to be given his night drugs or medications are changed. So until about, half past eleven, twelve, you cannot sleep yourself, because you always have to do something. He usually sleeps fairly early, I would say seven o’clock, plus or minus an hour, depending, it’s not always the same. If the night goes well, then you can sleep a little later, when the night goes bad, he wakes at one to two o’clock or sometimes three times a night, because he needs something or it could be that he is vomiting. Then he wets and soils himself and you must change the diapers. It can also happen momentarily, so that’s not always the same, the change that is different today.

For example, he was awake at half past three, four o’clock, he was agitated and couldn’t sleep, and he had soiled, then we have to just get up, then you just have to change everything. It can also happen that he has bowel movements, then you have to change him just wash him and everything in the middle of the night or in the morning. Then you try to calm him down to let him sleep a bit and you try yourself to get some sleep. Let’s say, at about six, six thirty he usually wakes but at six o’clock he must get his morphine. He needs to get Morphine, then he gets medicine for stomach protection. Then in the morning we let him just watch a little bit of TV, try to get a little rest. We have breakfast ourselves and then you have to wash him again, get him dressed and get him ready. At about nine clock the home nursing service comes, to check his medicine, preparing his controlled drugs and to be with him so that we can do something else.

Currently I am on holiday, so I’m at home, otherwise I try to go to work more often, if possible. Then my wife is here alone with the home care service, and if I do not go to work, then usually I’m just try to get out for a bit, to leave the house to do something rather than have to sit here forever. She stays at home in the morning because she does the housework and if it is possible she tries to get out in the
afternoon but she doesn’t do that as often as I do. She goes out much more seldom than I do. Once in a while she’ll go shopping. (…)

Or when I go to work, then I’ll come home early either for lunch or during the afternoon back home, so I try to leave work early. So then we can both be here. At midday, the Home care service leaves. We have tried to get a physiotherapist, once a week in the afternoon, but only recently. Then we are going to try to get more help in the afternoon but the person has only been once so far. And in the evening at some point he goes to sleep and everything starts at the beginning again. (…)

He has days where he drools all day from the mouth, because he does not swallow. He has days where it’s better, he has days where he vomits often a lot, he has days where he vomits a little. He has days when he is in a better mood, and days when he worse. So this also varies. But in principle he is bed-bound.

We have bought a big beanbag filled with Styrofoam balls, which you can shape a little bit, so we put him in there once or we put him on the couch sometimes or he is laying in bed, but there is nothing more. He is fed through a gastrointestinal tube, so we do not need to cook dinner! But in principle, he is tube dependent. Nevertheless, he vomits because he has stomach juices that come up the way. The food goes into the intestine, this probe caused him abdominal pain, because he has the tube. He still has stomach pain every day.

And yes, more or less the days are like that. (Int. #4)

Other parents were similarly exhausted by the demands of the intensive care that their child required:

‘Maria’ needs everything done for her, but I have pain in my back, I cannot do any sports, because I go to sleep. When the nurse is coming, because I am so tired, I cannot, even in the afternoon. If we have time to go to restaurants, to have a nice evening, I tell my husband, I am so tired, I am sorry I have to go to bed. (Int. #2)

I myself was so tired and I had nothing left, I had to sleep there and sit on the chair. (Int. #16)

For five years now I have been getting up at 5:30am, getting up at 5.30am is terrible. Before, we got up half an hour later and that half hour is crucial. I didn’t used to fall asleep on the couch on Saturday afternoons. But now I do it regularly, at 2pm I fall asleep. This is a lesson we have learned. (Int. #18)
One family uses the services of a children’s hospice in Germany for ‘respite care’ and to ‘charge their batteries’:

We go three times a year to the children's hospice, because 'Maria' has 24 hour one on one care with a nurse, and we can sleep in a different room one floor above. We can sleep through the night for two weeks. This is how we can re-charge our batteries, then our meter is back to zero, and not always down in the negative range. And then things are OK for a while.

We are getting close to the end of September when we can go back into the hospice. It has been six months now (M: That is far too long) and it's too long, so we're really tired, tired, tired. (Int. #2)

Few, if any, parents mentioned the need for, or their use of ‘respite care’. Respite, or ‘short term’ support is often part of a children's palliative care service, where parents build their trust in a service and a health professional enough to allow them to care for their child perhaps for an evening or a weekend occasionally. We asked participants if such a service would be welcomed by families in South Tyrol and the general sense was that it may not be well used. As one health professional explained:

So if the child is not doing well, then no mother would go away, at least not the ones that I know. If the child is OK, then yes, maybe be this could happen, but then they would go away with the child. If the child is not doing well, then no mother will go away. (Int. #6)

However, another health professional believed of respite care that:

That's the big problem is that it does not exist. Not only now in palliative care, but even just for parents who have a child with a disability. They are spending every day and night caring for the child and never really have the opportunity to even have a weekend free, or even at home, to have time with your partner and the other children. (Int. #5)

Many parents had effectively to learn how to be their child's nurse, as well as mother or father. While training to become a specialist children's nurse may take many years of practice and study, these parents seemed to be on a ‘fast-track’ course from Parent to Nurse with the added dimension that their ‘patient’ was also their child:
He had a venous catheter in place and so at home we looked after the drip. And so we have learned to do that too. It was quite stressful because I'm not a health professional, I don't work in the medical field at all. And the administration of intravenous drugs to a child of two and a half is not easy, (…) He was always sick, you could not even think of going out to work. (Int. #18)

The hardest part (of caring for our child at home) is the organising and coordinating, let's say in the beginning you are only just trying cope with the situation. (Int. #1)

His first hospitalisation lasted 15 days and there we were taught how to practically manage the disease. In reality this disease doesn't have a 'cure', but it's not palliative care. But the goal in both cases is for him to have a better quality of life. To have this quality of life, it is important for him to do his physiotherapy. And then in the hospital we were taught how to do this physiotherapy, that we started almost as soon as he was born. (…) In addition to this, there was the fact of having to learn how to administer the drugs. It was a total drama. (Int. #18)

We were abroad and the doctors there encouraged us that we would be able to take 'Maria' home. So we were taught how to do her necessary nursing care, so we were able to independently do things like changing her needles and everything that a nurse would have to do, simply we were able to care for her independently, so that from their point of view we were allowed to go home. #13)

But then she was still quite small, she only weighed 2.5 kg.

It was already hard at the beginning because the catheter they were using was for children, maybe four or five years old and was not intended for such small babies.

But my husband and I were there and we have learned how to catheterise her, my husband immediately learned that too, because he said that otherwise I could not move or go anywhere. I couldn’t be away for any more than two hours, I always had to be at home. In the meantime, even my mother can do it (the catheterisation) and my sister-in-law can do it (she is an aged care nurse), she can do it to. (Int. #16)

So I needed to teach my husband a lot more than I thought.

He is a super dad, but caring for 'Maria' needs a lot of things to be done … those ventilator settings, and both of us need to be able to set and adjust the ventilation
settings during the night. When ‘Maria’ gets sick now we must respond and adjust the ventilator. For the coughing assistance that we have to give, we do every day between two and four times a day as therapy. We have four treatment periods, where we gently move her, the whole movement, the joints really like to be moving normally. So these things are pretty normal for me, the ventilation settings, and the coughing assistance. (Int. #2)

Finding support from other parents

It is common when a child has a life-threatening or life-limiting illness that parents will seek out other parents whose child has the same condition. Parents can find valuable support and information from parents who are ‘in the same boat’ and who will understand ‘what they are going through’ as they too have similar experiences:

And then later, however, the meeting with other parents was practically illuminating, because we learned then that life goes on. Maybe their children were already in a wheelchair, and they were still able to laugh and have a joke. And that’s when we ‘got it’. And that was the moment when we began to see a little light. (…) because in the Association, they are absolutely competent people with lots of experience who know how to steer a way through this condition. (Int. #19)

Parents’ knowledge of their child’s disease was often exceptionally good. Propelled by the shock of learning that their child has a potentially fatal diagnosis and their desire to understand its meaning and implications, parents sought information from as many sources as possible. Beginning with the doctors and nurses within their child’s treatment circles, parents gathered information from other parents ‘in the same boat’, libraries, their professional networks, affiliated and voluntary organisations.

Worldwide, there has been a proliferation of ‘Support Groups’ and parent advocacy groups for almost every imaginable childhood illness and disorder. The growth of the Internet and social media has driven the growth of such groups exponentially as it is now easy for a mother in a small Tyrolean village with Internet access to ‘meet with’ and discuss issues with parents and health professionals from across the world.
However, among the parents that we consulted for this study, there seemed to be very little use made of ‘Parent Support Groups’ or of any groups specifically formed by or for the children and young people themselves. For example, in Australia there is CanTeen - The Australian Organisation for Young People Living with Cancer. This is a national support organisation for 12 - 24 year olds who are living with cancer and is the only organisation of its kind in Australia.9

One parent described the value of such an informal group when their child was in hospital:

Yeah, that's right there was a place to stay right next to the hospital, there were several rooms and a shared kitchen and that was actually pretty great. So in the evening we met up with the other families, mothers or fathers who were ‘in the same boat’ as ourselves. All of the parents were actually from the ICU so you could share stories and things. It was a change for us. In the evening every once in a while we might have a laugh and maybe go into the city. (Int. #13)

Another described the mutual support that she found when they stayed in a Children’s hospice outside of Italy:

That’s the benefit of going to the hospice, because the parents, they know. You can talk to these parents and they know what you are suffering from. It's not so important, that the child suffers from the same disease, but the parents are suffering from social isolation you cannot talk to normal people, they do not get it, they cannot understand it, that’s it. (Int. #2)

While for another family, it was the ‘useful knowledge’ of ‘the system’ that the other parents had that was valuable:

Here in (X) There is a group of parents of children with disabilities but ‘Maria’ is the only child with (X). All have other conditions.

I: And is this group of parents, this is something where you can get support sometimes, can talk about it?

M: Yes, just because they gave me at the last meeting there in April and there we have just talked about what a problem they had because there were then Representatives of the Association of Parents of Children with Disabilities and they have advised me then to go to the provincial government. I never would have thought of (…) Then I made an appointment and luckily it worked. (Int. #16)

The isolation of life-threatening or life-limiting illness

Having a child with a life-threatening or life-limiting illness can be a lonely, isolating experience. Parents told us that in South Tyrol:

...nobody talks about ill children. (Int. #2)

and that talking about your child who may be dying was even less acceptable:

But by and large, I have been quite alone, the worst time. I just have to cope alone because I just thought that you have to do this yourself because no one can help you. (Int. #9)

Some parents however, were isolated and very much 'on their own' and unable to bring themselves to access such a support network, even if it were available:

P: We have not, no direct, or shall we say, no connections. There are connections with other parents out there, but we could just not connect well, as you can hear yourself just so, by SMS or even by telephone. But here in South Tyrol, we have no group.

I: So, no contact with (Parent Support Group 1) in (City X) ?

P: No, not (Parent Support Group1). We are supported by the (Parent Support Group 2).

So this is the same organisation as (Parent Support Group 1), a doppelganger. But (Parent Support Group 2) is in (City Y) and (Parent Support Group 1) is in... They do the same, help kids with cancer.

P: Yes, definitely, we have no contact with such a group, and currently I can only speak for myself because now, they must speak for themselves, I think there just now is no desire now to meet with me in a group. (Int. #4)

Others became isolated from family and friends as the demands of their ‘new life’ in caring for their child at home were so intense:

Sometimes the right people just come into your life, but they are always other parents who are ‘fellow sufferers’. But all of the others have, I must say, shunned me. Maybe this was because I was simply, I was so busy, I have not had a minute to spare. I’ve had no time for leisure or a conversation or a meeting, the chance just didn’t exist. Because you have to shut down like a machine, and you have a laser focus straight ahead, there is just nothing else you can do. (Int. #9)
For another family, the danger of their child contracting an infection was serious enough to make them ‘warn’ family and friends and in doing so this had led to their gradual social isolation as ‘friends were falling away’:

Another difficulty in recent years has been trying to explain to all the people who are close to us, that they shouldn’t visit us when they are sick, or even if they have a simple cold, because this can cause him serious complications. Many friends have fallen away from us, we have lost contact with people because our life has changed. There are only a select few people who can understand. (Int. #18)

Another concern was raised by the parents of a child with an extremely rare disorder who found it difficult to connect with any other families who may have a similar child because of ‘privacy regulations’:

I: So, (child's illness) in South Tyrol, do you know any other parents whose child has this condition?
P: No.
M: We do not know anyone and we will not get to know anyone, because nobody talks about ill children.
I: Ah, that is interesting.
M: The paediatricians are not allowed to tell about other children, or patients they care for, even if they are being cared for at home.
I: Do you think that it has to do with the issue of privacy?
M: Yes, everyone tells us that they cannot talk about the people whom they care for, whether that is the home health care or the paediatricians or anyone. They tell us no names, they do not say anything.

So for example, I have contact with a child who has a medical condition, but only because I’ve met the mother in kindergarten. I know there are parents with a child who did not get enough oxygen during birth, lives in (City X). And I have just tried to contact families through the people I know and told them there is a study happening and it would be good if they could take part. (…),because otherwise no one will know that you are there (…),it's so difficult to make contact with anyone. (Int. #2)

One family recounted the isolation felt by their pre-school child as she spoke only Ladin:

Where we have the problem, of course, until now ‘Maria' has only spoken Ladin, we speak Ladin and until a year or two ago I had to accompany her to the hospital...
and stay there, I would do that anyway, but because she didn’t understand anything.

I: So she has learned no German?

M: No German and no Italian. Only when she started kindergarten then, they then started but she didn’t understand much, but now at school it works with German and Italian.

And then this language group (Ladin) exists only in South Tyrol. Most people speak either German or Italian and so she didn’t feel comfortable. (Int. #16)

Another key reason why parent support groups are so valuable is that parents are often very altruistic and have a desire to help other parents who are in the ‘same situation’ and who may have a child with a similar illness or condition. As this parent explained about their being contacted about another family:

We made a presentation about our little one with photos and everything, and if anyone asked, they can get our phone number, or address, and we are also willing to help any other families in the same situation. (…)

A colleague of mine came to me and asked, he said that he had a work colleague, I think, who has a sick daughter, he said can he come and see you or talk to you?

I said, no problem, I gave him our phone number, two, three or four weeks have passed, I had actually forgotten about it and then I got the phone call and it was Mr. ‘X’ who said ‘I am the person with the sick daughter and could I meet you some time’.

Then we met up in (City X) and went in to see them. They saw our child’s ‘Rehabilitation Buggy’ that was passed on to us and then we talked with them just normally which was good for them. We were very happy that we were able to help someone else. (Int. #13)

**When home becomes a hospital: caring for your child with a life-threatening or life-limiting illness at home**

Well, we always had in my head that we would take her home, only to go home. (Int. #13)

Studies have shown that parents in Italy are at a disadvantage, should they wish to care for their seriously ill child at home. Research consistently shows that parents value having choices and options but that their preferred place for a child’s
palliative care is at home. One very experienced health professional emphasise this point when they noted that:

Of those that I have followed I have not known anyone who wanted to stay here (in the hospital setting), they all strongly wanted to go home. (Int. #12)

Despite parents’ preference for home care, Italy was recently ranked lowest among six European countries regarding a child’s dying at home:

“The proportion of home deaths varied between 19.6% in Italy and 28.6% in the Netherlands and was higher for children dying from complex chronic conditions (CCC) in all the countries studied, varying between 21.7% in Italy and 50% in the Netherlands”. (Pousset et al., 2010, p.375)

The situation may be improving however, and at least one paediatric palliative home care programme for children with cancer in Italy has been described (Manfredini et al., 2006).

‘Gearing up’ to care for your child at home

In his last two months of his illness, the situation became very difficult, because other things were adding to an already difficult situation. Things became so complex that at home, this can be very difficult to master as a layman. (Int. #1)

It could be very difficult for parents who were caring for their child at home, reconciling the activities of providing care with the need to be there for their child as a parent. There were many reports of task-induced stress in areas related to getting enough sleep and rest, pain assessment, management and administration of medications and generally in seeing your child suffering:

Changing the needle, the constant aspiration, those were really bad. There were always tears rolling down her face. We no longer heard her voice through the tracheostomy tube, we saw only the tears … (Int. #13)

Parents could also find themselves in the unusual and often difficult position of having to ‘train’ or educate and watch over the professionals or visiting carers who may not have had the very specific practice knowledge related to the child’s particular care needs. One child, whose care alternated between the hospital and
home, had a very rare condition requiring specific care which was not easily mastered:

The problem with the home health care system is that there are no children's nurses, so they first had to learn themselves. That is why it was so difficult because every week we had to teach new nurses again about ‘Maria’, show them again and so on, until we eventually after a year so we called an ‘emergency meeting’ and said that this way will not work. There are too many people working with ‘Maria’ and for no benefit. This is not a ‘relief’, on the contrary, we are always having to check and make sure that everything has been done correctly and to teach and, teach again and again. (Int. #2)

The intensity of providing twenty-four hour care at home was demanding. For many parents, support services were limited to a few hours per week of visiting nurse or carer help. This usually involved help with specific tasks such as administering intravenous medications or administering a particular ‘therapy’, rather than actual relief care which would enable the parents to have a break. For many children, their care required very ‘specialised’ knowledge and thus normal avenues used by parents of well children were inappropriate. Parents could not, for example, simply ask their parents or family member to come in and ‘look after’ their child for them while they went out to work, or to a movie, or for a meal:

At home over the past two months, the room was set up virtually like an ICU and I had the advantage as the coordinator that I was supported by all departments with infusion pumps, with syringes, with material. (Int. #1)

Parents described a process of ‘Gearing up’ for the move from hospital to home that was unforgettable for parents, particularly for the sheer quantity of equipment and extent of ‘new skills’ needed so that they could care for their child at home. Parents described setting up what seemed like a ‘mini-hospital’ in the home, with most moving the child between their bedroom and a main family room or lounge where the child could be at the centre of the home and family. This ‘Gearing up’ with equipment was both physically and emotionally taxing for parents.

Parents were learning and undertaking ventilation, naso-gastric feeding, chemotherapy administration, specialist gastrostomy feeding, complex medications, advanced palliative care pain relief, complex physiotherapy / OT positioning and
movement exercises plus the increasingly complex ‘fundamental care’ of their child such as washing, toileting, playing and more. Throughout all of these, the added layer of complexity and existential difficulty for parents was that this was ‘their child’, ‘their baby’ - regardless of how old the child was.

They did this to enable themselves to provide care for their child at home. Parents felt it was vital that they learn these skills so that they could provide their child’s palliative care and treatment at home. Parents also believed that community and other support nursing services may have been unavailable to undertake such intensive care and would be unavailable at the often unpredictable and unsocial hours when such care was required. While some nursing and social service support was often available, parents knew that the child's care would be predominantly their responsibility.

Caring for your child at home: encouragement and discouragement

Families reported a mixture of different experiences related to being enabled to care for their child at home. In the best of examples, hospitals and health professionals were supportive, enabling, encouraging and helpful. In the most negative examples, they were oppositional and threatening.

The most positive and wonderfully well organised home care was described by a parent living in a remote home setting ‘in the mountains’. The most negative and distressing was experienced by a family who were threatened with police and legal action ‘if they took their child home’ to care for them. The latter parent explained:

> After the diagnosis was clear that the tumour was inoperable and that ‘Mario’ will die, which was about two months before he died, then we said we did not want to care for him the hospital any more, we just wanted the treatment and support of the hospital but to care for him at home. (Int. #1)

Perhaps the worst aspect of this threat was the suggestion to the parents from medical staff that they were considering ‘euthanasing’ their child at home. As the parent recalled:
No, it was not about prolonging therapy, it was just, we wanted good pain management and the (medical specialists) believed that we were not going in that direction, but going towards euthanasia. (crying) (Int. #1)

Not surprisingly, given this mistrust from the child’s doctors, the parents tried to ‘protect themselves’ by calling on the support of a very senior and influential medical colleague and by video recording all of their interactions and treatment episodes during their child’s home care:

We have therefore partly recorded the entire final phase on video, we have documented and recorded using video in case the doctors ever took us to court. It is an indictment of the doctors that we needed to have a document showing that we have acted professionally, that we didn’t just ‘let him die’ or let him suffer. And so we have everything documented and recorded on video. (Int. #1)

The impact that such a cloud of suspicion, created by health professionals, had on this family during their child’s final weeks of life can only be imagined.

There may well be distinct ‘cultural factors’ at play in both South Tyrol and Italy as a whole that explain the reluctance among some health professionals and children’s health services to ‘allow’ and encourage parents to care for their child at home if they wish. As Pousset et al state:

“cultural differences may also be of influence. In Italy, while for older people home death is desirable, young patients are often treated intensively in hospital even when death is imminent, whereas in the Netherlands a greater openness exists in accepting death (Costantini et al. 2000; Became et al. 2006). This is confirmed by studies showing that end-of-life decisions with a possible life-shortening effect are less frequently taken in Italy than in other European countries”. (Pousset et al., 2010, p. 381)

What these researchers suggest, and what some parents in our study experienced was the phenomenon of doctors who could not ‘let go’, who could not consider any other care option beyond ‘one more treatment’, another ‘last ditch’ intervention, or ‘one more cycle of chemotherapy’.
Such a medical mindset is well recognised within palliative care in general and within paediatric palliative care. At its heart may be the belief in medicine as magic, the doctor as the omnipotent rescuer and death of the patient as the ultimate personal and professional failure. As Beretta et al noted in one Italian study:

“Even the medical team looking after the child may erroneously experience the switch to a palliative treatment as a personal defeat”. (Beretta et al., 2010, p.89)

Within such a ‘defeat’ view, it is easy to see how palliation can become a ‘nothing more can be done’ abdication of professional responsibility. As one nurse recalled of a child:

Nobody thought about promoting and fostering the child because it was coded as palliative. (Int. #3)

Home nursing support

For most families in the study, there came a point where they knew that they would prefer to have their child at home with them, despite the challenges and difficulties of caring for a child with a life-threatening or life-limiting illness at home. In this respect, the families in South Tyrol echoed the preferences of other families worldwide where ‘home care’ with expert support is the preferred option of most families.

Health professionals who work in ‘the community’ as opposed to in a hospital have always appreciated that there is a different dynamic of care there, a different mindset and way of working when you are in a person’s home. Health professionals who worked with families at home encapsulated this well when they explained that:

At home, the caregivers and health professionals are guests of the family. But in Hospital, the parents are guests and that is quite a different feeling and situation. Unconsciously the question arises as to ‘Who is the boss’? In hospitals, the health professionals can ‘hide’ but not when they go to help a family in their home. (Int. #3)
Because of the political changes, children who need palliative care are being cared for in the community. So we, as paediatricians are now being confronted by children's deaths at home. (Int. #10)

Where home care worked exceptionally well was when the health professionals were flexible and prepared to offer the family the kinds of help and support that they wanted and that best met their needs and not the schedules or ‘policies’ of the professionals. This particular family’s experiences are highlighted as they show how excellent service can be provided even to a rural, ‘isolated’ family:

I was convinced that I would bring my child home. I couldn’t care less about anything trying to stop me. He is here, I’m here, we are going home. End of story. What happens around the trappings of care doesn’t matter and from the organisational standpoint, I have to say the nurses have never made an issue of helping me at home, there was never a problem. It was simply self-evident that it must work. I knew what needed to be organised and how it should look and the women themselves have simply said that, this was OK so it was clear that it would work. There was no discussion. This is difficult, for example organising a bed for ‘Mario’. I said, we do not need too many ‘special’ things, we will do it by adapting the ordinary things that we have at home. The nurses came with a car loaded with stuff, I said to them, don’t be worried, and we went upstairs. Then we looked in the room but as it was the room under the roof it wasn’t always the same height. They looked at it and said, OK we’ll give it a try. And so it transpired that it all worked out OK. We made do with what we had and so that it all worked out. We didn’t use any extra. We made it simple and flexible and that was how it worked best. (Int. #9)

The other key factor was that the health professionals respected the family’s wishes, trusted them and acknowledged their particular expertise. As one health professionals commented:

It is quite often the case that these parents know more about it than we do. (Int. #8)

Wood et al neatly summarise this parental expertise as being expressed in:

“technical care, for example, knowing or anticipating when there is a problem with drug regimes;

intimate care, for example, knowing how best to wash or feed their child or how best to make them comfortable;
**emotional care**, for example, being able to understand speech or expressions of discomfort that were not appreciated by other carers”. (Wood et al., 2010, p.802)

This mother explained how valuable it was to find health professionals who acknowledged this expertise and ‘took her seriously’:

Because even the nurses, it was (Nurse X) who always said we need to see what his mother says, because the mother knows the child best and if she says that he reacts this way or that, then we have to pay attention and trust the mother. I appreciated this because they attended to me and to ‘Mario’ (…). She said OK, if we need to then we can do it differently. She has always taken me seriously. (Int. #9)

This parent’s story exemplified how well home care support can work in children’s palliative care. This would have been a ‘difficult’ case for services as the family lived in a fairly isolated, rural home that would have been difficult to access, especially in winter. The parent described at great length how they received wonderful support from a health and social services team who cooperated and collaborated for her benefit:

Furthermore, I must say the nurses from the Community Services gave their full attention to the situation and if I have said he has noticed this or he has felt that, then they have taken me absolutely seriously in this respect. And they have actually done what I wanted. I'm quite stubborn in that respect, but I had no problems there because the team really respected and followed my lead. (…)

The care from Community Services was impeccable, I have to say they have tried to do everything they could within their boundaries and the beauty was that we could leave certain things out if we didn’t want them. As the mother of ‘Mario’, because I knew exactly what he wanted and what he would not want, and they have respected that. (…)

And we were never lacking for something, because if I needed something, they have immediately organised it. (Int. #9)

‘Going downhill’: the child’s condition worsens.

At some point in the child’s illness trajectory, parents became aware that they were not going to recover and that their child will die. This is a moment of supreme horror for any parent, a realisation that almost defies words. Some parents were told this
prognosis fairly clearly by medical staff while others gradually came to the understanding as they saw their child deteriorate:

I: How long did you care for ‘Maria’ at home?
M: One year, a little more than a year.
P: Until (date) she died at home. A doctor came to (City X) for a conference and asked us if he could see ‘Maria’ so he came to our home and told us that from his point of view she was already very ‘far gone’. And from that point on, ‘Maria’ has gone downhill. (Int. #13)

‘Mario’ said to me that the tumour was not going away. I then noticed immediately, that it no longer, he could not get up or walk, he went all downhill, so weird, he was always getting weaker and it was like a movie, one moment you are going uphill, the next moment you are going downhill. (Int. #9)

The child dying at home

Parents tried to balance many factors in deciding on where to care for their child or on the child’s place of death, such as the child’s own wishes, their own preferences, their perceived strength and ability to cope with the child’s life-threatening or life-limiting illness care needs and their own positive or negative perceptions and previous experiences of health care settings and health professionals:

From that moment, practically, he then spent a week in the intensive care unit without success due to his seizures and everything that goes with those. The doctors then said simply, that there are no more treatments available, and they cannot do anything more and they do not know how long he would live. They said we should think about taking ‘Mario’ home. (Int. #9)

In all the participating families in this study, where the child had already died, the place of death had been at home. One parents spoke for many, saying that,

“We just wanted us to enjoy the last time with him and to spend it at home, then ... (crying) (Int. #1)

The child’s place of death was influenced by several key factors. The palliative care ‘phase’ of the child’s care often came at the end of exhaustive treatment and care
programs that left both parents and their dying child drained and exhausted. Often, children had been ‘probed and prodded’ and had endured pain and distressing treatments and ‘therapies’ before it was acknowledged that the child was now approaching death. The child’s wishes were a major influence on parents’ choice of the place of their palliative care. In this study, for those children who were capable of indicating a preference, their choice was without exception, to die at home.

He finally died of lung problems and damage. He died at home. (Int. #15)

‘Letting go’

“And a part of you wished it would just end, said the monster, even if it meant losing her.”

From ‘A Monster Calls’ by Patrick Ness

The death of a child in contemporary times is fortunately a very rare event and one that has ‘moved’ in history, from children dying at home, to now predominantly going to hospitals. As such, many people have not had the opportunity to observe, know, and learn about dying other than perhaps from dramatised accounts viewed through film and television. Dying at home, once a common occurrence in the earlier part of the 20th Century, is an option which is commonly chosen, especially for children who are approaching death. I have previously identified the reasons why some of the participating parents in this study and their children, preferred to be at home rather than in a hospital at this time.

Parents of a child with a life-threatening or life-limiting illness will, one day, have to face the moment when they know that their child is approaching death, when it is time for their ‘hope’ to move from hope for a cure, to hope for a peaceful and love-filled death and when it is time for them to ‘let go’ together. These mothers recalled the moment when they “knew what was going on”:

P: In the afternoon it started at once, and I noticed that he was breathing the wrong way (…), I called the Community Service and the nurse with whom I had a really good relationship heard ‘Mario’ breathing and said she would be there right away. She almost flew in, it was so quick. She gave him his morphine, so he was a

bit quiet and then you could just wait and see. It was relatively quick because it started at about three clock in the afternoon and by 5.50pm he ...

I: He died?. He has fallen asleep in your arms?
P: Exactly. And thank God I was just at home with the boys. (Int. #9)

That was at some point in January, that was when we had a conversation with the senior physician of the intensive care unit, with this Professor, this neurologist and, yes, then he told us about the probability, that yes it could be, that the disease could be transmitted by us and that there would be 25% chance of any other children having the condition. This probability calculation that he told us ..., and even then he couldn't tell us how long ‘Maria’ would live but he said that she would not live longer than ten years. Naturally, yes at the beginning we had some hope but eventually we understood that we were really dealing with her remaining quality of life and thinking about how she could spend the rest of her life with us at home. (…)

It is important to accept that at some point there is simply nothing more that can be done, and then you need to start letting go. But that is also something very difficult. (…)

And from this point on, it has gone downhill rather quickly, and then there was that night, I still went to work that night, and then I just got the call from my wife that she couldn’t find a pulse, and by six clock in the morning, and yes, I drove straight home and then we were alone, and then we have called, our family. (Int. #13)

One of the most difficult things that a parent can ever say, or even think, is that ‘It may now be time for my child to die’. For one parent, the heartache of watching her child’s condition deteriorate as the various attempted treatments failed, while being unable to speak this truth, was almost too much to bear:

And then, so they actually have talked with me, ‘What do you want’ and I have said. Yes, he could die, I want … (Crying), but that was never an issue for them, and I also said …

I: So they did not talk to you about his possible death?
M: No. No. Not at all.

M: From the Children's Cancer Fund, in Germany, there's a book about Prince Lucifer, that tries to explain in a very nice way, that he has a very bad disease that involves ‘bad cells’, and chemotherapy fights the cells, but then there is also a princess who is cured and can go home. But what happens to the children who do
not go home cured? So it seems to me that there is always only an illusion and it is not open and honest, not even to the children or to us the parents. (...) This story doesn't ring true because it is not true that everything always goes well, I feel, it's too easy! It seems to me that there is no openness and honesty about talking about death. It is always pushed away to the back.

I: And you wished that they were honest with you about death so that you can prepare for it?

M: I will never forgive the senior physician, because he knew very well how ‘Mario’ developed his sepsis, and what ‘Mario’ has already suffered. At this point he should have said ‘Stop’ (Crying) You cannot do that to children.

Sometimes it is too much. (Int. #4)

Parents’ experiences of caring for their child with a life-threatening or life-limiting illness highlight the importance for health and community services of having the coordinated system and skilled professionals necessary to ensure that parents have the knowledge, information, power and compassionate support that will enable them to help both their child and themselves during these most demanding of times. A good starting point is to ask what it is that parents appreciate and value in their services and in their health professionals. From a starting point of listening to parents, it is then possible to move to considering the best policy and practice approaches to take so that such services for families can be provided in the sensitive, responsive and successfully ways.

What Parents Valued and Appreciated in Health and Social Services

Because, that human nature itself is often forgotten. Under the whole machinery, of medicine, therapies, because sometimes they forget that there is a small creature that can actually really say much more could they received it a bit.

Many things would go easier if doctors and nurses responded differently by looking just first at who is there, not just what do I need to do now. (...) First, look who's here, and then act. (Int. #9)
Every modern children’s health service and especially a children’s palliative care service would wish to be sensitive, responsive, flexible, supportive and above all - clearly child and family centred in both its philosophy and operation. While many services claim such qualities, parents may view the services quite differently. As one parent mentioned in the survey, a service can have fine words that bear no resemblance to the actual services received:

There is much Blah Blah, but little help (Survey Response)

In both surveys and interviews we asked parents to tell us about services that they had received that were valuable and about attributes and qualities of health professionals and services that they especially appreciated. Their suggestions and examples covered areas such as the physical environment of hospitals and wards, the services they used and the personal attitudes and approaches of particular health professionals.

Services and supports used by parents were both professional and personal, formal and informal and varied according to the child’s condition, what was offered or available and what parents could find for themselves. Parents understood (or discovered very quickly) the extent of the commitment involved in choosing to care for their child at home, while facing a future that was both unknowable and unthinkable. They expected that there would be adequate support available to help them meet their overarching imperative - that they must meet all of their child’s needs and give them ‘the best life possible’ within the strictures and threats of their life-threatening or life-limiting illness. As this parent explained:

Yes, at first, of course, we still had hope that a diagnosis would be found that meant she would live. But at some point in time, we realised it is really just about the quality of the rest of her life that remains, and for her to spend the rest of her life at home. (Int. #13)

Nurses were the most frequent health professionals who visited the child at home and their value for some parents was greater than their instrumental functions as injectors, wound dressers or equipment providers. Parents had a very clear recollection and appreciation of the professionals whose caring practices enabled and supported them during this time. Often, this was the professionals who were
perceived as ‘going that extra mile’ for the child and parents, what one parent called:

...a relationship that goes beyond. (Int. #18)

Parents valued professionals who took time to spend with them, even when they were clearly ‘busy’, who made it clear that they were ‘really’ approachable and available to parents and who had the flexibility of approach that made parents feel ‘in control’:

Because even the nurses, it was (Nurse ‘Maria’) has always said ‘we need to see what his mother says, because the parent knows the child best’ and if she is saying that he reacts this way or that, then we have to respond well and trust the mother. (Int. #9)

What parents valued

- A genuine ‘team approach’ from health professionals. “Here is a team, there are doctors, there are two physiotherapists, there is a nurse.” (Int. #18)
- People and services who were genuinely ‘child-centred’, who could see the child and family as real human beings rather than just a collection of symptoms, a diagnosis or a technical problem. “See the child as a whole and not only organ-specific” (Survey)
- Consistency in having the same nurse(s) - ‘Primary Nurse’ rather than constantly having to welcome and ‘train’ new staff in the home. “A nurse dedicated to me”. (Int. #18)
- Health professionals who genuinely cared both for and about them and their child. Health professionals with ‘humanity’, compassion and kindness. “It was really almost a friendly relationship.” (Int. #13)
- Health professionals who “took them seriously” and who listened carefully and respectfully to them. “Take the parents seriously, they are in most cases not just the specialists in their child but also about the disease.” (Survey)
- Health professionals who were honest and open, who could tell ‘the blunt truth’ but with compassion, not brutality. “Be open, honest and humane”. (Int. #2)
• A service that was responsive and quick-acting and that understood that parents often ‘cannot wait’ for urgent action, supplies, and support. “We were never lacking in something, because I needed something, they have immediately organised.” (Int. #9)

• Health professionals who understood that they would prefer to bring their child home to care for them rather than have them in hospital, but that they needed their help and support to do this. “Understand that with a seriously ill child, care is preferred at home, rather than living in the hospital. (Survey)

• A ‘key person’ or ‘named person’ who was the parents’ point of contact and who could make decisions and ‘make things happen’ to help them. “Just a point of contact, as I have said before that I find very important.” (Int. #13)

• Health professionals and services who understood that ‘the little things’ in the child’s and parents’ lives were vital and paid attention to these. “They have therefore truly informed me about even the smallest thing.” (Int. #9)

• Health professionals and services who were flexible rather than policy and rule-driven. Parents’ and their child’s situations could change rapidly and no two families were ‘the same’ and so a ‘template’ approach to care was not welcome. “The assistance is to be flexible and adaptable, so that it is not a rigid system.” (Int. #2)

• Health professionals whose approach was to work with the family, not on them and whose philosophy was ‘How can we best help you to give your child the best life they can have’.

• Health professionals who were confident in their ability to help, knowledgeable and competent and who were willing to share that knowledge and expertise with the parents. “She (the nurse) gave me complete confidence in every respect.” (Int. #9)

• Health professionals who had special expertise and skills in working with both life-threatening or life-limiting illness and with children. “A special children’s nurse was looking after us and another two were
really familiar with the care and were really a big help for us.” (Int. #13)

- Health professionals who were accessible and contactable. “We were always connected by phone.” (Int. #9)

- Children’s wards, units and areas that are designed for children, not adults. “The clinic is very nice, the decor is very well done, it's really great, it is a children's room.” (Int. #2)

- Health professionals and services who put aside any professional ‘egos’ or rivalries and who collaborated and co-operated with others for the benefit of the child. “Cooperation with specialised Centres here and abroad.” (Survey)

- People and a society that accepted their child and accepted and understood that life-threatening or life-limiting illness in a child, or a child who was dying was ‘part of life’.

- The opportunity to know about, meet and find support among other parents ‘in the same boat’, either in person or online.

- Health professionals whose expertise and advice helped their child to be as pain-free and symptom-free as possible. “Good quality of life of the child, no pain. No shortness of breath at night.” (Survey)

We also asked parents to tell us about any services that would have been valuable and helpful for them. Here, parents either described existing services that were not experienced as valuable and in their view, needed to improve. These were often the opposite of the qualities described in the list above.

Parents also suggested a range of supports and services that were not available. These were the services that they wished were available in South Tyrol and that may have made it unnecessary for them to travel to other parts of Italy or into Austria or Germany.

**What parents wanted**

- More information concerning intervention and technical aspects of care.
• Medical and nursing specialists for children with life-threatening or life-limiting illness.

• Physicians to take more time for talking with parents and for explaining the illness, the treatment and its consequences.

• Health professionals who are better informed about the best available treatment options. They should not ‘automatically’ suggest the one centre.

• The option of where to care for their dying child, whether this be at home or in the hospital. Preferable or desirable option: Dying at home. Wishing to care for your child at home should be acceptable and not seen as a ‘difficult request’, ‘poor choice’ or ‘hot topic’ (Int. #13).

• Therapy services provided at home (home visits).

• A named and accessible ‘expert’ contact person, Physician or Nurse

• Cooperation and sharing between South Tyrol health system and the different Centres in North Italy and elsewhere (being knowledgeable of what they can offer).

• Cooperation between South Tyrol health system and the different Centres in North Italy and elsewhere in such a way, that care can be organised in proximity of their own home.

• Integration of sick child in the kindergarten and offering care at the kindergarten to ensure that child’s life is as ‘normal’ as possible.

• Sufficient professional nursing hours provided at home to enable the family to ‘function’ while caring for their child. (This depends on the situation, the illness, health status of the child, and the parents’ energy/tiredness levels from the demands for caring for their child).

• Professional, specialist paediatric nursing care from nurses who understand children, family-centred care and life-threatening or life-limiting illness/paediatric palliative care.

• Honesty in policies and politics concerning the situation of sick children.

• A Pediatric ward is often not the right place for teenagers and young adults. Consider facility that caters for adolescent/young people’s special needs.
• Health services and health professionals should work more closely with parents’ support groups and the special ‘Associations’ for specific illnesses, e.g. Cystic Fibrosis Association, Peter Pan, Muscular Dystrophy, Childhood Cancer etc.

• Flexibility must be the basis of services as parents’ particular needs and the child’s changing condition often cannot be ‘predicted in advance’.

• More ‘family-friendly’ opening hours and convenient locations of supporting services (e.g., hospital pharmacy not having “9-to-5” standard hours).

• Start a discussion and dialogue about how parents can consider and talk about a ‘Living will’ or ‘Do not Resuscitate’ plans for their child. This is a very delicate topic and parents want to be able to discuss this without being labelled as: “I am the worst mother in the world, because no mother does this” (Int. #4).

• A dedicated Case-manager for complex cases.

• A greater emphasis on children’s palliative care and support for children living with a life-threatening or life-limiting illness within health professionals’ educational programmes and continuing education.

• A greater awareness from health professionals that ‘Hospital care’ does not simply ‘translate’ across to care in the family home. Adapting care of the child to care by the parents at home with professional support requires flexibility and mutual trust from both parents as caregivers and health professionals as supporters and enablers.

• Health services that are always humane, human and focused on putting the child and family first.

• Flexibility from nursing staff.

• Parents wanted the Department of Health and senior politicians and policy makers to create a ‘system’ that helped and enabled parents, making their lives as easy as possible. They did not want a ‘system’ that was bureaucratic, difficult, slow, difficult to understand and that they had to constantly ‘fight’.
• Parents wanted well-qualified staff, building trustful relationships between different services and across different health districts. It should not be ‘luck’ or a ‘gamble’ as to whether your local service is good.
• Better trust, sharing and cooperation between different services (e.g., health services and the school/education system) and across different health districts.

The Health Professionals’ Perspectives

We involved a wide range of health professionals who are or have been involved in providing care and services for children with life-threatening or life-limiting illnesses. Thirty health professionals completed the online survey and ten were interviewed. These are the various health professionals who completed the survey:

<table>
<thead>
<tr>
<th>Role</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children’s Nurse</td>
<td>7</td>
</tr>
<tr>
<td>Nurse</td>
<td>6</td>
</tr>
<tr>
<td>Hospital Doctor</td>
<td>3</td>
</tr>
<tr>
<td>Paediatrician</td>
<td>2</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>2</td>
</tr>
<tr>
<td>GP/Community Doctor</td>
<td>1</td>
</tr>
<tr>
<td>Community Service Manager</td>
<td>1</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>1</td>
</tr>
<tr>
<td>School teacher</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
</tr>
</tbody>
</table>

D8+IT8:Q1 - Can you please tell me your role? (N=30)
Most health professionals who completed the survey worked in hospital, rather than in a community service:

![Bar chart showing most health professionals work mostly in hospitals.]

Their experiences of working with children with a life-threatening or life-limiting illness ranged from rarely to regularly:

![Bar chart showing the frequency of working with seriously ill children.]

We asked health professionals for their views and experiences of existing services and asked them to describe or suggest ways in which service provision could be improved. We also asked them what kind of paediatric palliative care services would be most appropriate for South Tyrol.
A pediatric palliative care service does not exist. (Int. #12)

Health professionals generally agreed that there was no specific or dedicated service available for paediatric palliative care:

Many health professionals commented that while they and their colleagues provided palliative care and support for these children and families, this was uncoordinated and reliant on the enthusiasm or ‘goodwill’ of particular staff. As these health professionals commented in the survey:

- Again and again it depends on the personal dedication of individuals
- There is no satisfactory coordination within the structure,
- there is at the moment not really a good organisation in this area.
- There are no special services are available for paediatric palliative care
- To my knowledge there are so far no explicit interdisciplinary pediatric Palliative care.
- In South Tyrol, as far as I know, there is no service
- There is not a team of professionals that advise and assist locally
- In our Department, palliative care is not part of a service, officially, but they are an integral part of the department.
• very often the quality of the service provided is given by the goodwill of personnel, of the physician-nurse
• There is a lack of an organised network

The health professionals generally felt that existing services were not as accessible and as good as they should be, with most suggesting that they were ‘poor’ or ‘very poor’ and that they are not meeting the needs of the families as they should be:

D8+I78:Q6 - From your experience, how would you describe the availability and quality of palliative care and support services for these children and families? (N=22)

- Excellent. As good as could be found anywhere in Europe
- Very good. Perhaps with some gaps in services
- Average. Fairly well developed but could be much better
- Poor. There are very few services available
- Very poor. There is really no children's palliative care service available in South Tyrol

0 1 2 3 4 5 6 7 8 9 10
Poor understanding and acceptance of palliative care for children

Health professionals were asked for their views on how the term ‘palliative care’ was viewed and received among parents, families and the wider community of South Tyrol. Overall, their understanding as expressed in the survey question and ‘open comments’ seemed to be that people ‘had trouble’ with the term, due to its many negative connotations:
for many it has something to do with the word palliative, that "nothing more can be done "the child cannot be saved" (in the sense of healing).

- there are large differences in awareness what ‘palliative’ means.
- Palliative care is not yet widely used in the population in South Tyrol. They have difficulties with this term.
- It is not explicitly used by the resident physicians and put into practice.
- this term also includes a high emotionality on the part of parents: it is very threatening when their own child can no longer be cured.
- because it is connected to the idea of imminent death.
- In professional circles it, ‘palliative’, is often equated with “dying soon”.

Health professionals in South Tyrol are expressing views that would be very familiar in many countries, even those where paediatric palliative care has been more successfully introduced and where those working in the area may believe that ‘the public’ are more enlightened and accepting of concepts such a dying and death.

The research literature on paediatric palliative care, particularly within the Italian context would support their concerns. Studies in Italy consistently show a marked cultural aversion to discussing or facing the many challenging issues surrounding
dying and death. Such reluctance may well be multiplied when it is a child or young person facing death (Benini et al., 2011a; Campione, 2004; Floriani).

Health professionals’ ideas for paediatric palliative care in South Tyrol

The key suggestions for paediatric palliative care service improvement from health professionals were:

- Parents / families need more information from physicians. Parents / families should not have to always search the internet.
- There should be a specialist paediatric palliative care service and team established with specialised knowledge and backgrounds and who are easily accessible. There is a demand for such a service and it would not be too difficult to establish one.
- Parents also need health professional specialists who do home visits and who will help them care for their child at home.
- Therapy services (such as speech therapy, physiotherapy) are also required for children with a life-threatening or life-limiting illness.
- Parents need a contact person so they can care for their child at home and who is accessible at all times.
- Have a ‘Contact point’ or ‘Central / Focal point’ for parents – which gathers all the necessary information that parents need.
- Families need pediatric nursing support at home and at the times and hours that are valuable for them. Home nursing services already exist in the community, but these families need specialist pediatric nurses.
- A ‘Case manager’, would be both valuable and appreciated. This would be a kind of ‘travel agent / travel companion’ who would help and support the family through this illness trajectory or ‘journey of illness’. This person would ‘know the system’ and would be able to ‘keep all the different threads’ together. ‘What is missing is a case-manager for these families’. (Int. #11)
- A paediatric palliative care service must make it possible for families to care for their child at home.
- A paediatric palliative care service that would consider and support the ‘whole family from a 360° angle’ would be very important for
parents, siblings, grandparents and all of the other people who are involved.

- Improved health professional training and education in paediatric palliative care and in the particular skills and approaches needed to work in partnership with families and to support care in the home. This should be within ‘basic’ paediatric health professionals education and at post-graduate/continuing professional development levels.
- Establish Internships for health professionals within South Tyrol’s different services to help build trusting relationships between hospital and community services.
- Offer similar ‘Internships’ to enable staff to visit and learn from the world’s best children’s hospices and other paediatric palliative care services and to bring this knowledge and skill back to South Tyrol.
- Create appropriate qualifications for staff in paediatric palliative care and family-centred support for children with life-threatening or life-limiting illness.
- Ensure that humane, sensitive communication is not seen as ‘the icing on the cake’ but as an essential part of health care and a fundamental skill that must be demonstrated by all health professionals.
- Ensure good cooperation between hospital and community services.
- A Children’s Hospice for South Tyrol could be a good idea but there would be problems of culture, language, attitudes etc to address.
- A dedicated paediatric palliative care service would be a good thing, an Interprofessional palliative team with different health professionals and expertise, but they must consider the spiritual and psychological realms as well as the child’s ‘medical illness’. This service also has to be ‘mobile’ and able to visit and support families where they live.
  “Provide a central coordination point and a team of doctors, nurses, certainly psychologists, which thus forms the core and then it is just like a network” (Int. #14).
- Having a team of people in every health district who can care for these families/children.
• Establish a Centre for paediatric palliative care, led by a person with specialised training and who is competent leading such a Centre in a humane way.

• It should be a high political priority: to establish a paediatric palliative care team that is responsible for South Tyrol, not only for the hospital but also for the community services. The team members should be prepared to help and support families in an easy going, flexible manner.

• A centrally coordinated paediatric palliative care service that is always easy to get hold of.

• Create a service with a lean, efficient, bureaucratic structure (so you don’t need five documents for one request).

• The MoH has to give sufficient time and dedicated resources for such a paediatric palliative care service to be established. It cannot simply be ‘added on’ to people’s existing work and roles.

In hearing from the health professionals in their interviews and in reading their survey responses, it was notable that so many saw the existing situation in South Tyrol in a very similar way to that of the parents. Most felt that the existing service provision situation for paediatric palliative care and the care of children with a life-threatening or life-limiting illness was unsatisfactory, ad hoc, uncoordinated and in need of reform.

Most suggested that a dedicated, specific paediatric palliative care service, of some kind, needed to be established and that there would be strong support for such a service both among health professionals and families:
They believed that this service should be multidisciplinary, flexible, responsive, un-bureaucratic, province-wide, well educated and trained and grounded in a humane and child-focused, family-centred philosophy. The parents in this study would assuredly agree with this and would be both appreciative and supportive of such a service.
The Child’s Survey

It was disappointing that only one young person was able to complete the Children & Young people’s survey. It is still important however, to value this young person’s contribution by including it in this report.

The young person who completed the survey was a 14 year old boy who identified as Italian. His illness was a rare neuromuscular disorder. The survey asked young people to think of four words or phrases that described how they felt about their illness? He replied:

‘it is not so bad’, ‘sometimes bored and lonely’, ‘mostly good’, and ‘ambitious’.

He has met a few other young people with the same medical condition and is quite open about talking to friends and other people about his illness. He said that:

I stand by it and I do not care what the others think. (D2 Survey)

When we asked about what was bad or scary about the illness, he told us that it was the fact that there were so many things that he couldn’t do, either by himself or with friends or schoolmates.

This young person had a good, open relationship with parents and health professionals and was able to ask questions and talk freely about his condition. He did not identify any questions or issues about his illness or his life that he would feel unable to ask about. He also agreed that there were no occasions when he had been unable to get information about his illness from health professionals.

When we asked for three things that adults could do to improve the lives of young people like him with a serious illness he suggested:

Invent better medications and equipment so you can live better.

Be there for everyone.

Wheelchair accessible transport everywhere so that we can be more independent.
We also asked what staff in hospitals could do to improve things for young people like him. He told us that he wanted health professionals to be:

- To be there for me 24 hours a day if needed
- To keep providing free help as long as possible
- To be ‘nice’ and ‘sympathetic’
- And … To talk with me not just about my illness but also about other, private things.

Like many young people however, he would rather not have to spend time in hospital if at all avoidable. His ‘one thing’ about hospitals that he did not like was “if I hear that I have to stay longer.” When we asked what things would make a hospital stay better, he was very clear:

- Large windows and lots of light. A good TV and electronically adjustable beds.

Perhaps without realising it, this young person has identified a key aspect of a healing and therapeutic hospital design - the presence of good windows and an abundance of natural light and contact with the ‘outside’ (Raanaas et al., 2012; Bromley, 2012; Shattell, 2011; Ghazali and Abbas, 2010; Ampt et al., 2008; Verderber and Reuman, 1987; Ulrich, 1984).

Lastly, when we asked what famous people he would most like to have met, the list was impressive: ‘Lionel Messi, Steve Jobs and Leonardo Di Caprio’.

**Limitations of the study**

As with all studies, this study has several limitations. When researchers report small-scale, predominantly qualitative studies such as this, it is always wise to be cautious and not to over-generalise findings by suggesting that they would be applicable to all populations, cultures and settings. This study does not claim to be ‘the last word’ or the definitive statement that speaks for all parents of children with a life-threatening or life-limiting illness or all health professionals in South Tyrol. It is a modest, one year initial exploration of the views, experiences and perspectives
of three vital ‘stakeholders’ in the world of children’s health care - children, parents and health professionals.

This study reports on a comparatively small sample group of parents and health professionals. Like all researchers, we would have liked greater numbers in our study and were disappointed not to be able to involve more participants. However, as Tan et al (2012) note:

“Difficulty in recruiting for Palliative Care projects is well documented”. (Tan et al, 2012, p.46)

It is also perhaps an indication of the sensitivity and ‘unspoken’ nature of the topic, and of just how busy parents are with the demanding everyday care of their child, that more parents were unable to participate.

The number of respondents may seem ‘small’ as a subset of all parents in South Tyrol, however, when taken as a subset of the much smaller group of parents whose lives have been directly touched by having a child with a life-threatening or life-limiting illness, then the response rate seems less discouraging.

Part of the study was to be an exploration of the ‘child’s voice’ - children’s and young people’s perspectives of living with a life-threatening or life-limiting illness. Despite our best efforts to tailor a survey and interview approach to be as ‘child-friendly’ as possible, only one young person completed the survey. If we wish to make sure that our services are truly ‘child-centred’ and ‘child-friendly’, this question of accessing ‘the child’s voice’ remains an important area to be explored and perhaps other researchers in South Tyrol will take up the challenge.

A final and important limitation of the study was the challenge of language and translation and the considerable additional time and work that this took within the study. It was invaluable having the help of my research colleagues at Claudiana (MMK, LL, CM-G) who translated all of the surveys, interview guides, and other study documentation into German and Italian. The major language challenge was however the interviews and the subsequent analysis of transcripts and surveys.
We would ‘debrief’ after each interview and discuss what had taken place, what had been said, what the ‘emotional tones’ had been etc, but of course, this is no substitute for hearing an interview in your native language. While we were able to have the interviews transcribed verbatim (in German or Italian), we did not have the significant funding required to have these professionally translated into English. I used a paid software programme called ‘EasyTranslator’\(^\text{11}\) to translate the interviews and surveys and then sought clarification from the research team. This was a ‘workaround’ solution born of necessity but not the ideal approach.

To ensure that the initial ‘EasyTranslator’ translations were as faithful to the original German and Italian transcription meanings as possible, the research team (PD, MMK, LL, CM-G) checked and discussed each participant’s quotation and comment cited in the report against the original interview transcript and corrected these when necessary.

‘What can we learn from studies with such small numbers?’ is a frequent criticism of studies such as this. The great ethnographer, Harry Walcott provided the answer when he explained succinctly: ‘As much as we possibly can’. (Darbyshire, 2004, p. 22)

## Conclusions

### The parents’ ‘journey’ or ‘trajectory’: being in the ‘driving seat’

If there is a unifying narrative that runs through the parental and health professional accounts and comments gathered in this review, it might be expressed in the metaphorical question of ‘Who is in the driving seat?’ (Brett, 2002) concerning the care and treatment of children with a life-threatening or life-limiting illness, or as Shields et al asked about hospitalised children in 2003, (Shields et al., 2003), “Who owns the Child?”

\(^\text{11}\) [http://www.acetools.net](http://www.acetools.net)
When a couple become parents and have their much loved and anticipated child, they are very much 'in the driving seat'. The parents choose the child’s name, their clothes, their foods, their schools, their holidays and more. However, when parents receive the diagnosis that their child has a life-threatening or life-limiting illness, it seems that they are given a passport to ‘another country’ - a land of illness, treatment, tests, procedures, specialists and often suffering for their child. Not only that, but they find that they may no longer be ‘in the driving seat’ regarding their child. Now it may be a health professional who is driving. Worse may follow if the car now seems like a London taxi or limousine with glass windows separating the parents from the driver, and from their child in the front seat. The parents are no longer ‘in control’ of their child or their life, they may not know the destination or route travelled, they may feel unable to attract the attention of or communicate with the new driver and may feel like little more than helpless and passive passengers.

Both parents and health professionals in this study sought a system of paediatric palliative care and support for families where a child has a life-threatening or life-limiting illness that is more collaborative and that allows parents to remain ‘in the driving seat’. Perhaps a better metaphor for future health services for these families would be the idea of the ‘shared driving’ that families will often do if they go on a long ‘road trip’ or holiday. The parents share the driving, both know where they are going and how to get there and the ‘work’ is shared. ‘Shared driving’ with health professionals should be integral to the philosophy of FCC that should underpin any new paediatric palliative care service established in South Tyrol.

In describing the vital characteristics required of a service and its staff who are caring for families and children with a life-threatening or life-limiting illness, Jankovic lists ‘Accompanying, listening and respect’ (Jankovik, 2012). These are staff who know how to be a sensitive and respectful ‘travel guide’, they know how to ‘be with’ people during such a difficult journey and they know how to bear witness to love, hope, suffering, dying, heartbreak and grief.

There is much more to be said about this concept of the parents’ and families’ journey or ‘trajectory’ through their child’s initial diagnosis, treatments, remission/recovery or perhaps, sadly, their child’s death. The implications of such ‘illness
trajectories’ for children with a life-threatening or life-limiting illness, for parents and for health professionals will be explored in greater detail in a forthcoming journal paper based on this review (Noyes et al., 2013; Henly et al., 2011; Zelcer et al., 2010; Menezes, 2010; Wood et al., 2010; Kralik et al., 2006; Murray et al., 2005).

**Taking this work forward in South Tyrol**

This has been a very timely study, highlighting the current state and future possibilities for children’s palliative care and for the ongoing care and support of children with a life-threatening or life-limiting illness in South Tyrol. As Benini et al (2008) note nationally, the government of Italy is keen to follow through with the National Public Health plan that emphasises how:

“particular attention must be paid to the need for palliative care in neonatal, pediatric and adolescent age”. (Benini et al., 2008)

The plan also stresses that:

“it is indispensable to organise dedicated palliative care networks for this age group that can guarantee the quality and specialisation of the action needed together with a global and multi-dimensional care for the children and their families”. (Benini et al., 2008)

For paediatric palliative care, the time for action is certainly ‘now’ and there is no good reason for delaying the process of transforming services for children with a life-threatening or life-limiting illness.

In many ways South Tyrol and Italy as a whole lags behind other parts of the world where dedicated paediatric palliative care services or facilities have been established for many years. Unlike other European countries, such as the UK, South Tyrol, for example has no children’s hospice (Gold, 2009; Hain, 2005; Jackson and Robinson, 2003) or other dedicated service specifically devoted to paediatric palliative care and the specialist support of children with life-threatening or life-limiting illness (Schmidt, 2011; Bona et al., 2011; Hawley, 2010;
Vadeboncoeur et al., 2010; Siden et al., 2009; Dabbs and Butterworth, 2007; Hays et al., 2006; Friedman et al., 2005).

This situation can however, be used to South Tyrol’s advantage. With no ‘history’ of children’s paediatric palliative care South Tyrol has very much a ‘blank slate’ upon which to create the most suitable, appropriate and evidence-based service for the people of the Province. There are many examples of excellent services that South Tyrol could draw upon and learn from as it designs and develops its own response to what the parents and families in this study have explained is required (Balaguer et al., 2012; Rogers et al., 2011; Fondazione Maruzza, 2009; Knapp et al., 2009; Gold, 2009; Liben and Papadatou, 2008; Wright et al., 2008; Davies et al., 2008, ACT, 2003; Contro et al., 2002; Higginson et al., 2002; Levinson, 2000; Dangel et al., 2000).

Listening to parents and health professionals: learning from the best

The families have clearly expressed the ‘foundations’ and ‘guiding principles’ of the desired service of the future. They want to be respected for their knowledge and understanding of their child. They want to be acknowledged as the ‘expert parents’ that they are (Shaw and Baker, 2004; Tattersall, 2002). They want their child’s wellbeing and quality of life and that of their whole family to be at the core of the work that health professionals do and at the heart of the relationship that they have with both health professionals and health services. They want to be confident, that in South Tyrol, the 21st Century is indeed, “The Century of the Patient” (Gulland, 2011).

They have also highlighted many of the very practical and logistical features that would also need to be incorporated. What the families and health professionals identified as hallmarks of the system and service that is required echo many of the existing recommendations from other reviews, reports and recommendations internationally describing what a modern paediatric palliative care should be like.
The ‘blueprint’ or plan that they have offered has been put into practice in other paediatric palliative care and support services for children with life-threatening or life-limiting illness. For example, services that I am personally familiar with through my previous research and my current consultancy work have addressed many of the problems and issues that South Tyrol is currently facing in creating their services.

In my ‘home State’ of South Australia (SA) we have a paediatric palliative care service that is nurse-led, multidisciplinary and that provides a predominantly home-based service for approximately 50-70 children/families in any year.12 There is no Children’s Hospice in SA as it was felt that this was not the most suitable model for the state. Although SA is around 133 times larger than South Tyrol it has only perhaps three times the population (1.5m) with Adelaide as its capital city centre and with extensive rural and remote areas.

The Waikato region of New Zealand is similar to South Tyrol in many ways. The populations are similar at around 400-500,000 and Waikato has a major city - Hamilton, with many surrounding rural and farming communities and smaller towns. The main service in Waikato is Rainbow Place - a nurse-led, children’s palliative care, family support and grief and bereavement support centre.13

In establishing a model of paediatric palliative care, South Tyrol can explore several possibilities, including the creation of a Children’s Hospice, a hospital based paediatric palliative care team or a wholly community based paediatric palliative care team. However, given that the building of Children’s Hospices has fallen out of favour recently, this may not be the most cost-effective or parentally favoured option. Pertinently here, in a recent Swiss study, the researchers discovered that among parents and families:

“The provision of hospice services did not emerge as a solution of high priority”. (Inglin et al., 2011, p.1035)

13 http://hospicewaikato.brandish.co.nz/how-we-help/rainbow-place/
This matches my own experiences in researching and supporting the development of children’s paediatric palliative care services in Australia and New Zealand. Australia has only two children’s hospices (a third one was closed amid poor care and neglect claims (Elsworth, 2009).

New Zealand’s Waikato Region has what I believe to be a ‘best of both worlds’ model that South Tyrol could consider emulating. Rainbow Place is the children’s palliative care and grief and bereavement service. Rainbow Place has been in operation for ten years and moved into a new purpose-built premises approximately five years ago.

Rainbow Place is NOT a Children’s Hospice. It began in 2003 as a support service for families where a child had a life-threatening or life-limiting illness and for bereavement support for parents whose child had died. A few years ago it moved to a new purpose built home as part of the larger ‘Hospice Waikato’ (A non-government organisation). The adult hospice and Rainbow Place children’s service share the same grounds and are both part of Hospice Waikato.

Rainbow Place, like South Australia’s paediatric palliative care service is a multidisciplinary service. Both services have acknowledged expert senior nurses as their service leaders with both advanced level qualifications and considerable clinical and service leadership experience. This is because most of the work of children’s palliative care and of providing home-based support for parents and families who have a child with a life-threatening or life-limiting illness is holistic nursing care of the child and family. Of course, the services liaise closely with medical and other health professional colleagues such as paediatricians, GPs and local hospitals and refer on and seek advice from specialists whenever required, but the heart of the service is family-centred care and the spirit of the IMPaCCT standards (European Association of Palliative Care (EAPC), 2007), not a concern for traditional professional hierarchies.

Rainbow Place supports children from birth to older teens and helps families from the point of referral/diagnosis, through the illness, beyond the child’s death and into parental and sibling bereavement. Most of the counselling and children’s nursing
staff of Rainbow Place work in the community and with families at home but they also liaise with and give specialist expert support to hospital staff, health professionals in other areas, teachers and schools and anyone else who needs advice on how to help support these families, children and young people. Rainbow Place is the centre of expertise, advice and support in the region.

As a facility, Rainbow Place has spaces for counselling, children’s activities, artwork, group meetings, various recreational and psychological therapies and more. They also have three ‘rooms/suites’ where parents and their child can stay for ‘respite care’ (Ling, 2012; Bowman et al., 2011; Strunk, 2010; Pascuet et al., 2010; Nageswaran, 2009; Eaton, 2008; Thurgate, 2005; Davies et al., 2004; Ingleton et al., 2003; Beale, 2002; Valkenier et al., 2002), or if the child wishes to come for a ‘sleepover’ or ‘fun night’ with other children who use Rainbow Place. Each room has a place for the parent(s) to sleep and the child has their place in the adjoining space. Each room has its own kitchen and bathroom and is more like a very small ‘hotel suite’. These ‘rooms’ can also be used for other purposes if necessary. For example, most parents prefer if their child is helped to stay at home as their death approaches so that they can die at home. However, should a child or parent(s) NOT want their child to die at home, Rainbow Place can use their ‘rooms’ for this if that is the family’s choice (Darbyshire et al., 2012).

There are so many other positive features of the Rainbow Place ‘model’ that, in my view, would make it worthy of very serious investigation and consideration by South Tyrol as it moves forward with its plans to develop its own modern paediatric palliative care service.

**The time for change is now**

Researchers often conclude their reports with a plea that ‘more research is needed’. In the case of paediatric palliative care in South Tyrol this is only partially true. No further research may be needed to show that the current services provided are not consistently meeting the needs of such a vulnerable group of children and parents. No further research is required to tell us what the principles and foundational approach of a valued paediatric palliative care service for children with
a life-threatening or life-limiting illness should be. These things we know and the parents who shared their experiences in this study have reinforced their relevance and applicability for South Tyrol.

Research will however continue to be vital. It is vital in improving our knowledge of what constitutes effective and valuable care and supportive interventions across the wide range of children and young people of different age groups, cultures and backgrounds. It is vital in deepening our appreciation and understanding of the worlds of the children and families who face the crisis of a child’s life-limiting illness. It is especially vital in evaluating the new programmes and initiatives to ensure that they meet the ultimate test of quality assurance: that this is what each of us would wish for in a service if it were our own child who had the life-threatening or life-limiting illness.

In a recent commentary on the factors that are impeding the development of quality paediatric palliative care services worldwide, Hinds noted that much work still needs to be done to combat:

“the factors that limit advances in paediatric palliative care, such as inaccessibility, slow spread of knowledge, fragmented care, insufficient medications, uncontrolled suffering, incomplete approaches to family-based care, and poor communication”.

(Hinds, 2012, p.107)

To identify and understand these factors as they apply in South Tyrol, as many of the parents and health professionals who contributed to this report have done, is an important first step. The next step is to use the considerable existing knowledge and the creative capacity of South Tyrol’s health professionals and their national and international colleagues to create a paediatric palliative care service for South Tyrol that avoids such pitfalls.

It is often claimed that change and improvement in health care is a slow process and that people ‘must be patient’. Langiano (2012) points out that in 1894 in Italy, there were specific pediatric hospitals in Turin, Cremona, Rome, Palermo, Genoa, Naples, Florence, Alexandria, Como and Livorno. Children’s hospitals such as
these, social paediatrics and advances in child psychology in general, have led the way in ‘humanising’ child health care through the Family Centred Care (FCC) philosophy. FCC directly challenges the belief that it is the ‘health system’ and its needs that are at the centre of care and reminds us that it is the child and family (Langiano, 2012).

The suggestions in this report do not require South Tyrol to ‘start from scratch’ or to ‘re-invent the wheel’, but to build on these foundations established over 100 years ago. Parents of children living with a life-threatening or life-limiting illness have been waiting long enough.

Over 15 years ago, in South Australia, I concluded an earlier research study into paediatric palliative care provision with a comment that seems as relevant now in South Tyrol as it was then in Australia. The parents, children and young people, and health professionals in South Tyrol who shared their experiences with us, asked in similar ways to be at the heart and epicentre of a distinct and dedicated paediatric palliative care service for children with a life-threatening or life-limiting illness. To create such a service that is truly ‘family-centred’ and ‘whole child-focused’:

“We need the humility to listen to parents before we plan services for them. We need to learn from them before we presume to teach them. For only from a basis of such shared understandings can a system of genuinely shared and humane care evolve”. (Darbyshire et al., 1997, p.185)
References


Charlton, R. (1996) Medical education - addressing the needs of the dying child. Palliative Medicine, 10(3), 240-246.


European Association of Palliative Care (EAPC) Taskforce (2007a) IMPaCCT: Standard Per Le Cure Palliative Pediatriche In Europa. Un documento redatto dal Comitato
Guida della task force EAPC sulle cure palliative per bambini ed adolescenti. European Journal of Palliative Care, 14(3), 109-104.


Ferrante, A., De Sero, F., Lazzarin, P., Dalla Pozza, L.V. & Benini, F. I bisogni delle famiglie con figli affetti da gravi patologie inguaribili. RICP 2010; 1: 24, 33,

Floriani, F.C. (2009) FCP: Why Italy is a special case when it comes to palliative care. European Journal of Palliative Care, 16(4), 204-206.


defined by interviews with parents who made phase I, terminal care, and
resuscitation decisions for their children. Journal of Clinical Oncology, 27(35),
5979-5985.

Palliative Nursing, 18(3), 107.

Qualitative Health Research, 15(9), 1277-1288.

and discussion of the literature. Palliative Medicine, 17(7), 567-575.

Inglin, S., Hornung, R. & Bergstraesser, E. (2011) Palliative care for children and
adolescents in Switzerland: a needs analysis across three diagnostic groups.
European Journal of Pediatrics, 170(8), 1031-1038.

International Work Group on Death Dying and Bereavement (1993) Palliative care for
children. International Work Group on Death, Dying, and Bereavement. Death
Studies, 17(3), 277-280.

Social Policy, 23(1), 103-112.

and pediatric palliative care nursing education (510). Journal of Pain and Symptom
Management, 39(2), 411-411.


Clinical Journal of Oncology Nursing, 14(4), 514-516.

Stories of Families Who Move to Seek Inclusive Educational Experiences for Their

Knapp, C., Madden, V., Marston, J., Midson, R., Murphy, A. & Shenkman, E. (2009)
Innovative pediatric palliative care models in four countries. Journal of Palliative
Care, 25(2), 56-60.

Perspectives. Springer Verlag,

Knapp, C., Madden, V., Marcu, M., Wang, H., Curtis, C., Sloyer, P. & Shenkman, E.
(2011a) Information seeking behaviors of parents whose children have life-

Knapp, C., Madden, V., Wang, H., Sloyer, P. & Shenkman, E. (2011b) Internet use and
eHealth literacy of low-income parents whose children have special health care
needs. Journal of Medical Internet Research, 13(3),


Model for Pediatric Palliative Care. American Journal of Hospice and Palliative Medicine, 28(3), 161-170.


