NARRATIVE ACCOUNTS OF PARENTHOOD FOLLOWING THE DEATH OF A CHILD TO MUSCULAR DYSTROPHY

In 2015, the University of Hertfordshire was approached by The Muscle Help Foundation to evaluate the impact of the Muscle Dream experiences they offer to young people with a diagnosis of Muscular Dystrophy (and other muscle wasting conditions) and their families.

In this summary document, we report on a subsequent research project that evaluated how parents who have lost a child to Muscular Dystrophy describe life *with their child and following their child's death.*

The Muscle Help Foundation aims to deliver 657 Muscle Dreams to young people with a diagnosis of Muscular Dystrophy, which is one wish fulfilment experience for every muscle in the human body. Up to 2017, 267 Muscle Dreams have been delivered

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RESEARCH

AIM OF RESEARCH

The aims of the research were to explore the ways in which parents experience parenting a child diagnosed with muscular dystrophy. This included an interest in what seemed to be important moments in a parent's story, the ways in which these are understood to bring meaning to difficult circumstances, and how these influence an individual's, parent's and family's sense of self. Existing research highlighted that the time of diagnosis, important developmental milestones, the young person becoming an adult, and decision-making and planning for end-of-life care as important matters to hold in mind. We were also curious about how families develop and grow together to face not only challenges, but opportunities that they encountered in relation to Muscular Dystrophy, such as the Muscle Dream experience.

HOW THE RESEARCH WAS DONE

Ethical approval for the research was sought from University of Hertfordshire Health and Human Sciences ethical committee.

We interviewed five couples in depth about their experiences of parenting. We used narrative inquiry, a method of research that explores the ways in which stories tell others about the events that take place in our lives. We analysed over 10 hours of interviews to explore the families overall accounts, including experiences across the lifespan - such as stories of seeking a diagnosis, to experiencing a Muscle Dream event.

Narrative analyses look at:

- What we talk about (content);
- How we talk about things (how we structure/order and express them) and;
- Why we retell experiences in particular ways, at particular times and in particular places (meaning, purpose, intention).

As we interviewed a small group of parents, it was important for us to anonymise these accounts significantly. Details are provided in the wider report but for the purposes of this overview, anonymised quotes are used.

FULL REPORT (available from authors):

Randall-James, J. (2018). Narrative accounts of parenthood following the death of a child to muscular dystrophy. Thesis manuscript.

RESULTS

WHAT WE FOUND

Stories of change

Waking up to different futures

Parents described how receiving a diagnosis of Muscular Dystrophy was a particularly defining moment for their family, especially in terms of their envisioned futures as parents.

"I think we mourned the loss of [him] then, that's how I feel. We couldn't see the wood for the trees at that point"

Such moments of change in one's envisioned future, was said to have a significant personal impact on the parent's wellbeing and sense of identity:

"I changed that day, that diagnosis come and I, I've never been right since to be honest. Only now he's no longer with us, I'm different again. All these things in life, the impact it has...it changes you, inside and out"

"I was in so much bits"

Couples recounted numerous experiences throughout their parenting journey, in which changes in their child's health pushed them to reappraise their vision for the future – such as when their child could no longer walk independently, choices relating to independent living, and decision-making around the dying process.

"It comes, you know, completely out of the blue, really, and we were knocked sideways immediately"

Being so close, you don't see the deterioration

Couples talked about the relentless need to be in 'the present moment' whilst caring, which meant that deterioration in their child's health would be experienced as unexpected and sudden.

"I was unaware of the condition and everything at the time...so I was quite oblivious to everything at the time and I just saw past it every single day"

"Do you remember I said he'd go off his feet?" ..."But that was quick"...and she went, "It's been going on for years", because you know you just get so used to things as they are and then donk, It's another change"

Stories of surviving

Storytelling together

An important part of the couples' accounts were the ways in which they supported one another to talk about painful memories in great depth whilst maintaining their emotional safety and security. At times, this could involve steering away from the sadness in order to return to it at a time when it could be less distressing.

WHAT WE FOUND

Stories of surviving

Humour through the struggle

All couples interviewed detailed how humour would connect family members throughout their journey, particularly during more challenging times. As one parent say, "it's a forever process of struggle and laughter". At times, humour was purposely used to overcome difficult circumstances – such as facing tough decisions, hearing difficult news and trying to manage obstacles and lack of access to opportunities in the lives of their children.

"The one thing we always did with [our son] was...we always tried to turn a negative into a positive because that's the only way you can survive...to make things right for your family, you have to find the funny side, don't you -and the positive side... It's hard sometimes though"

"He is dying"... it's always the same talk...they tell you these things but each and every time, he proved them wrong... [laughs]. He showed them the middle finger basically! [laughs]"

Humour was also used as a way to 'fight' or 'resist' inequalities, discrimination and unfairness commonly faced by the young people living with Muscular Dystrophy. Parents often used humour as a 'safe' way to share painful memories and experiences both in the research interviews and in life.

Stories of creating change

Creating a legacy, making a difference

The couples interviewed talked of how their children inspired those that personally knew them – influencing the relationships around them.

"I still draw strength from him, I always will do. Without a doubt"

"He was the core, weren't he? He was the cog ... he just constantly... got on and did things, but the inspiration from him I think is the sheer love for life, knowing ... in his little head, there's not much ahead of him but it didn't stop him"

All couples talked of the significant and long-lasting impact their children had made to their local and wider communities. Many of the parents compared their son's achievements to themselves and/or others, often in admiration for their achievements.

"From his point of view...if we couldn't get it, then how could any other child get it, and he wanted to do things better for those coming after him"

Stories of creating change

Living the dream

The couples talked of how the Muscle Dream event created freedoms from things usually inaccessible to the young people and how it was pivotal in creating memories for all involved.

"Making memories is what it's all about"

Importantly, the Muscle Dream experience was said to 'lift' the young people and their parents during emotional testing times.

"The Muscle Dream experience gave a lift, it makes you feel special at a time where life doesn't necessarily make you feel very special"

"I felt special and I'm only Mum, so God knows how my son felt"

Our findings that support previous research:

In line with existing research we found that:

- Receiving a diagnosis of muscular dystrophy introduces significant change to a young person and their family's life.
- There are few 'breaks' when caring for a young person diagnosed with muscular dystrophy.
- Parents understandably face challenges to their own mental wellbeing as they ceaselessly protect, love and care for their child.
- Parents often overcome challenges through joy and their use of humour that connect and bring families together when facing adversities.

What we found that is new:

- Diagnosis of muscular dystrophy has significant implications for parental identity: with changes in who they see themselves becoming, what their relationship could become, and particular dreams for their child's future.
- Having the opportunity to retell and 'story' the impact of their child's life, was painful and difficult at times, but deemed therapeutic.
- Parents often use humour in retelling painful stories in order to give permission to others to not become overwhelmed, to hear their struggle, and to be able to respond/take action at some level (for example, to consider responses to discrimination/social exclusion).
- Wish fulfilment events, such as the Muscle Dream experience, provide the opportunity to experience enabling environments and discover new opportunities: creating a context for re-building identity around stories of resource and strength.
- Having the opportunity to explore and share the legacy of their children may be helpful in processing experiences of loss and bereavement.

RESULTS

CONCLUSION

This research strengthens our understanding of the numerous and significant changes that a diagnosis of muscular dystrophy brings to a family's life. We found that couples will face multiple changes and challenges to how they imagined their life would unfold when their child received a diagnosis of muscular dystrophy. Through facing these challenges, the parents learned new ways to overcome adversities together and with their child.

The research found that caring for a child on a daily basis could make it difficult for parents to see the broader picture of the young person's deterioration, and when they did, it was often humour that enabled them to survive and overcome painful experiences. While remembering their lives with their children with joy and humour, parents also told painful stories about life with muscular dystrophy, including the exclusion and discrimination young people living with disability often still face in our society. This highlights again the importance of continuing efforts to work towards an inclusive and enabling society.

Parents described that it was through taking part in events like the Muscle Dream, involvement in the community and contributing to the care of others, that their children left a lasting legacy. This research supports the idea that Muscle Dream events help parents to make sense of the loss of their child in a way that helps them move forwards, offering not only an emotional and psychological 'lifting' within the experience itself, but also in part, sustaining parents throughout their bereavement. Those providing care to young people living with muscular dystrophy and their families can consider putting families in touch with organisations like the Muscle Help Foundation as part of a full package of care.

The Muscle Help Foundation is a unique, multi-award winning, small charity, rooted in family values, delivering transformational experiences in the UK called 'Muscle Dreams' for children and young people (8-28yrs) with the muscle wasting disease, Muscular Dystrophy (MD) and allied neuromuscular conditions.

Since inception in 2003, the charity's vision has grown from a big idea, to a life changing reality, touching the lives of thousands of people across the UK. Today, it's impact and reach continues to grow.

With your support, the charity will surpass its target of delivering 657 'Muscle Dreams', that's one life changing experience for every muscle in the human body. To learn more about its impact, get involved and discover how your support can help change lives and give hope, contact us today – as we say, that's the #powerof657

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