

Chronic Illness

<http://chi.sagepub.com>

The lived experience of hope among parents of a child with Duchenne muscular dystrophy: perceiving the human being beyond the illness

André Samson, E. Tomiak, J. Dimillo, R. Lavigne, S. Miles, M. Choquette, P. Chakraborty and P. Jacob

Chronic Illn 2009; 5; 103
DOI: 10.1177/1742395309104343

The online version of this article can be found at:
<http://chi.sagepub.com/cgi/content/abstract/5/2/103>

Published by:



<http://www.sagepublications.com>

Additional services and information for *Chronic Illness* can be found at:

Email Alerts: <http://chi.sagepub.com/cgi/alerts>

Subscriptions: <http://chi.sagepub.com/subscriptions>

Reprints: <http://www.sagepub.com/journalsReprints.nav>

Permissions: <http://www.sagepub.co.uk/journalsPermissions.nav>

Citations <http://chi.sagepub.com/cgi/content/refs/5/2/103>

RESEARCH PAPER

The lived experience of hope among parents of a child with Duchenne muscular dystrophy: perceiving the human being beyond the illness

ANDRÉ SAMSON*, E. TOMIAK†, J. DIMILLO*, R. LAVIGNE*, S. MILES†, M. CHOQUETTE†, P. CHAKRABORTY† and P. JACOB†

**Faculté d'éducation, Université d'Ottawa, 145 rue Jean-Jacques-Lussier, Ottawa, ON K1N 6N5, Canada*

†*Children's Hospital of Eastern Ontario, 401 Smyth Road, Ottawa, ON K1H 8L1, Canada*

Received 2 November 2008, Accepted 17 February 2009

Objectives: Duchenne muscular dystrophy (DMD) is genetically determined, progressive and incurable. Our study's primary objective was to describe the lived experience of hope among parents of a child with DMD.

Methods: Semi-structured interviews were conducted with 12 parents having a child with DMD. A qualitative/phenomenological approach was utilized to analyse the essential aspects of this experience.

Results: We show that the experience of parental hope emerges from the cognitive appraisal of DMD. The child's illness can be perceived in three ways: as a severe loss, a call to adapt or a way to rediscover the child. Each of these appraisals leads to different ways of hoping. Parents can hope for a cure, the child's well-being or to see their child becoming a whole person. Hope can help parents absorb the initial crisis, sustain their adaptation or prepare for the fatal outcome.

Discussion: Previous research has demonstrated that cognitive appraisal plays a central role in psychosocial adaptation to illness. Our research indicates that perception can also shape the nature of hope and suggests that health professionals should pay particular attention to the nature of parental hope. The fabric of parental hope can give an indication of how parents are coping and adjusting.

Keywords: Parental hope, Childhood chronic illness, Cognitive appraisal, Duchenne muscular dystrophy (DMD), Psychosocial adaptation

INTRODUCTION

Duchenne muscular dystrophy (DMD) is the most common form of childhood muscular dystrophy and is genetically determined, progressive and incurable. Lack of the protein dystrophin, encoded by the DMD gene, leads to progressive loss of motor function, beginning in early childhood, and to loss of ambulation, resulting in wheelchair dependence, usually by the teenage years. The disease is uniformly fatal.

Median survival for individuals affected by DMD is currently 17 years, with few individuals surviving beyond the third decade.¹ Many affected boys exhibit some degree of cognitive impairment^{2,3} and the majority will develop cardiac complications after age 18 years. Respiratory complications are frequent and contribute to early mortality.¹

Jacob⁴ has described four distinct clinical stages in the evolution of DMD: early ambulation phase (ages 2–5 years), late ambulation phase (ages 6–9 years), early wheelchair phase (ages 10–13 years) and late wheelchair phase (ages 14 years and older). Each has characteristic challenges

Reprint requests to: André Samson.
Email: asamson@uottawa.ca; fax: 613 562 5146

and unique needs to be addressed by the multidisciplinary healthcare team, including genetic counselling and testing, optimization of physical function, pharmacologic therapy, assessment of respiratory function and discussion of assisted ventilation and palliation.

The clinical course of children with DMD follows a well-defined pattern of loss of specific skills, progressive deterioration and ultimately death. Losses are compressed into a short period of time and the constant evolution of disability precludes periods of stability, where families feel confident with trusting the care of their child to outside caregivers. The nature of care provided is constantly changing. The expectation of the ultimate outcome, however, is uniform: the inevitable death of the child.

DMD has been described by Nereo *et al.*⁵ as a 'complex chronic condition' with effects on the family similar to both chronic and terminal illnesses. They describe the following psychological adjustments encountered by the family in this situation: facing separation and loss; experiencing and expressing emotions; and changing values, expectations, roles and responsibilities. The complexity of this psychological adaptation, not surprisingly, results in considerable stress in families caring for a child living with DMD.

Theoretical research indicates the importance of psychosocial adaptation among individuals impacted by chronic illness.⁶ According to Cohen and Lazarus,⁷ perception plays a central role in the process of adaptation. In other words, the cognitive appraisal of the illness determines how individuals adapt.⁷⁻⁹

Cohen and Lazarus⁷ identify two types of cognitive appraisal: (a) primary appraisal and (b) secondary appraisal. The process of primary appraisal results in different ways of conceptualizing the impacts of the illness on one's well being. The situation may be construed as 'stressful, benign-positive or irrelevant'. The key point is that each appraisal can produce consequences that may facilitate or impede the process of adaptation. Secondary appraisal consists

of evaluating coping resources and alternatives in order to deal with the difficulties, restrictions and demands the illness imposes on life. It is secondary appraisal that allows the adaptation process.

The diagnosis of a chronic illness does not affect individuals in a uniform way because the experience itself is a function of their perceptions, interpretations and understanding of what is happening. In other words, the experience of illness is shaped by unique insights of the diagnosis.

In the specific context of DMD, the primary appraisal includes the realization that DMD is an incurable, progressive, debilitating and chronic illness. The secondary appraisal implies the mobilization and development of resources and abilities necessary to cope with the specific challenges associated with the illness.¹⁰

The objective of this research is to study the lived experience of hope among parents caring for a child with DMD in the specific context of psychosocial adaptation to chronic illness. In particular, the intention is to describe and to understand how hope emerges throughout the trajectory of the illness, considering the fatal outcome.

THE IMPORTANCE OF HOPE IN COPING AND ADAPTATION TO ILLNESS

According to social sciences research that has been conducted in the realm of health-care, hope has been found to play a fundamental role amongst ill individuals, their family and friends as well as their caregivers.¹¹ Nevertheless, there exists considerable difficulty in defining and making operational the concept of hope and a standard definition does not exist.¹²⁻¹⁶ A comprehensive definition of hope would need to take into account the dynamic reality of hope, having both cognitive and behavioural dimensions. At the same time, it would need to encompass the intangible element associated with spirituality.

A definition of hope that takes into account its multidimensional character and its complexity and richness has been proposed by Farren *et al.*¹⁷ According to these researchers, there are four main elements in the definition of hope. These are: an experiential process, a spiritual process, a rational thought process and a relational process. The experiential aspect refers to the fact that individuals are ultimately responsible for the charting of their own lives. The spiritual aspect of hope implies that hope transcends the material reality that can be observed. The rational or cognitive aspect of hope implies that this phenomenon is lived through goals to be achieved. This aspect situates hope in the context of a personal history where the individual is able to give a direction to his or her own existence. Finally, the relational aspect of hope implies that hope is constructed in relation to our own sense of connectedness with others.

In summary, hope is a phenomenon defined by the possibility of an individual to take charge of his existence, to give it direction and to transcend the simple material aspects of reality. In addition, hope exists because we are relational beings, called to be in communion with others. The individual is able to hope because he is free, responsible, transcendent and connected to other humans.

In the healthcare literature, hope has often been viewed as an essential prerequisite to coping and adaptation to illness.¹³ On the other hand, the absence of hope has been found to have a negative impact on one's psychological and physical well-being.¹⁸

In the specific context of healthcare, and according to most recent research, hope is an inner resource, which allows individuals to transcend the constraints imposed by illness in order to extend one's existential horizons. Therefore, hope is a positive orientation towards the future and the anticipation of an improvement. This anticipation can be either cognitive or behavioural in nature.¹²⁻¹⁶

While there exists extensive research examining the role of hope among patients

living with various medical conditions such as cancer,^{14,19-23} HIV,^{24,25} heart disease¹⁸ and in the specific context of palliative care,²⁶⁻²⁸ little research has been conducted on the lived experience of hope among parents with children or adolescents with a chronic, incurable and potentially fatal illness.²⁹ According to our own literature review, no research has of yet been conducted on parental hope in the context of DMD.

Despite limited knowledge on this very specific topic, existing research demonstrates that for parents caring for a child with a chronic, incurable and potentially fatal illness, hope is a basic inner resource. More specifically, hope can help sustain parents' efforts in caring for their ill child.^{30,31} According to Kirpalani *et al.*,³² parents' hope also has the potential to influence their child or adolescent's quality of life. Overall, parental hope is intimately intertwined with the experience of the child's illness.³³

Kylma and Juvakka²⁹ found that parental hope, in the context of adolescents living with cancer, could be endangered and engendered by very precise factors. Among the factors endangering parental hope, these researchers identified the adolescent's health status and deteriorating illness trajectory, a difficult economic situation, a perceived flaw in provided care, limited personal resources and poor social support. The factors engendering parental hope consisted of improvements in the adolescent's health and his personal growth, care meeting the needs of the child, sufficient parental resources, adequate social support, spiritual resources and finally, a positive orientation towards the future.

METHODS

Choice of Methodology

As the intention of this study is to describe the natural lived experiences of the participants in their own contexts, the use of the

holistic-inductive paradigm is most appropriate. Among the methodologies of the holistic-inductive paradigm, a phenomenological approach meets the objectives of the research. In qualitative research, the phenomenological tradition is rooted in the philosophical approach developed by Husserl.³⁴ For Husserl, the foundation of knowledge rests on the subjective experience. In other words, reality is not in the objective world, but in the way that it is perceived by the individual. In the phenomenological tradition, various data analysis methods have been developed.³⁵

The Empirical Phenomenological Psychological data analysis method proposed by Karlsson³⁶ was used in this study. This method is divided into five stages, which were followed in the present research. The first in the process is to carefully read and reread each individual participant's testimony in order to arrive at an empathetic understanding of the participant's experience. In the second stage, each verbatim is separated into individual units of meaning. Each new topic raised in the verbatim is a new unit of meaning, always seen within the context of the entire testimony. During the third stage, the units of meaning of each verbatim are interpreted and an initial abstraction of the meaning is made. In the fourth, each verbatim is interpreted to the highest level of abstraction possible in order to draw out the essential elements of the experience as perceived by the participant. Finally, in the fifth stage, the common elements of testimony are identified and the essential elements described.

Entry Criteria and Study Recruitment

To be eligible for study, parents were required to have a child with muscle biopsy or molecular study proven DMD, at any clinical stage, and needed to be able to communicate in either English or in French. Participants were given a choice as to which language they would use to complete the interview. Study participants were recruited at the Neuromuscular Clinic

of the Children's Hospital of Eastern Ontario (CHEO) between March 2007 and February 2008. In addition to the 12 study participants, an additional 10 parents were approached but they declined to participate in the study. Mothers and fathers of children with DMD were first approached by one of the members of the clinical team who had regular contact with the child with DMD. Signed informed consent was obtained prior to the completion of a demographic questionnaire and prior to the interview. The study protocol and consent form were approved by the CHEO Research Ethics Board.

Interviews

Each of the 12 participants was individually interviewed by one of three investigators (AS, RL and ET). None of the three interviewers were members of the clinical team caring for the child. Participants were asked to describe his or her experience of hope in living with a child with DMD, using a written Question Guide (see Appendix). Interviews were taped and later transcribed. The average length of the interviews was 90 minutes. In all of the interviews, only three types of interjections were to be made by the interviewer. First, if the participant stopped talking for a prolonged period of time, he or she was asked to re-read the question. Second, if the participant's comments seemed to be unclear, he or she was invited to clarify them. Third, if the participant spoke too quickly, he or she was asked to stop so that his or her testimony could be transcribed accurately.

RESULTS

Demographics

Demographic details of the parents who participated in the study are presented in the Table. Twelve parents from nine families were interviewed. Both the mother and the father were interviewed for three families. In all but two families, there was one boy

TABLE. *Parent and child demographic information*

Demographic variable	Ratios and ages
Mothers : Fathers	7 : 5
Median age of parent	48 (range 41–60) years
Median age of child	15 (range 7.5–17) years
Median age of parent at time of diagnosis of DMD in child	40.5 (range 31–50) years
Median age of child at time of diagnosis of DMD	5 (range 2.5–8) years
Median time elapsed since diagnosis of DMD	10 (range <1–13) years
Urban : rural home	9 : 3
Education level : high school	2/12
Education level : college	4/12
Education level : university	5/12

with a diagnosis of DMD. One father reported on his experience of raising two sons with DMD, while one couple reported on their experience of caring for a daughter with DMD. In two couples interviewed, the parents had adopted the child with DMD. One couple described their experience of looking after their son who had been diagnosed with DMD at age 3 years and who died at age 11 years, 2 years prior to the interviews.

Themes Identified

Analysis of the interviews identified three major themes and three sub-themes within the parents' experience of hope. Major themes identified were: (1) Facing the Loss, (2) Learning to Adapt and (3) Beyond the Loss. The three sub-themes identified were: (1) Context, (2) Coping, and (3) Fabric of Hope.

Facing the Loss

Context. The period immediately following the disclosure of the diagnosis of DMD is characterized by shock, grief and a profound sense of loss. Although many parents suspect something is wrong with their child, the severity of the diagnosis is overwhelming and provokes many emotions. The grief experienced by each family is manifested in

a unique manner and can be represented on a continuum. At one end of the continuum, the grief experienced by parents is hidden, or suppressed. At the other extreme, the grief experienced by parents is clearly observable, even to the extent of a major depressive illness. The early stages of the illness are also characterized by a sense of profound loss. Participants feel that they will be deprived of all the joys and expectations associated with parenthood: seeing their child growing, becoming a mature individual and actualizing their aspirations. After receiving the news of the initial diagnosis, participant 1 explains that:

At first I couldn't sleep the first week because I was picturing him in a wheelchair when he was still running around. He was still a happy boy, but I was picturing too far into the future. It really scared me. I was sick I think for a good 6 months. There was always something coming up.

The participants also experience deep feelings of insecurity towards the future. They are unsure whether they will have all the abilities and resources necessary to cope with the demands of the illness. They are also uncertain whether they will be able to fulfil their new roles as parents of a child with a disability. For instance, participant 6 described the parents' experience of the initial diagnosis as:

...experienced a great deal of worry. What are we going to do, how are we going to deal with all of this. Are we going to maintain health for a long period, are we going to be able to take care of them, are we going to have to institutionalize them. We went through various scenarios.

In summary, the parents perceive the illness as a stranger, an external and destructive force that threatens to destroy the child, and to a certain degree, their present way of life. Their perception is that an extreme solution is needed; a scientific miracle provided mainly by research and medicine.

Coping. Initially, the parents believe that they do not possess the resources that are needed to cope with the situation, they look for an 'emergency exit'. Their initial source of hope

(an external miracle, or cure) is in line with their passivity in dealing with the new circumstances. As they are unable to find a source of hope in the context of the illness, the parents are looking for something that does not exist: a miracle, a cure. Participant 9 illustrates this hope when describing the initial reaction to the illness:

I was hoping that we could stay strong to encourage him and hoping to be able to keep him around long enough and to have him stay healthy enough so that the research would have enough time to find a way to deal with a lot of the problems from DMD, and eventually, of course, a cure.

When the illness is perceived as an outside force, coping is mainly cognitive in nature. The parents believe that through research, medicine will provide an instant and definitive cure to the illness. In that sense, they are condemned to a certain passivity; they have to wait.

In keeping with this attitude of waiting, parents also engage in some limited forms of active coping. These include: seeking-out information on the Internet, as well as consultation with the medical team. Parents will also seek emotional support from family and friends. For example, participant 1 describes the experience as wanting to be proactive and having the need to:

... learn how to cope with this terrible news, and not feel like everything was falling apart. Which is maybe why I was sick all the time, I don't know. And then once it started to get better, then it's like I could take one thing at a time, and coming to the group as soon as we did, when he was quite young, that really helped too.

Fabric of hope. The cognitive appraisal of the illness as an insurmountable threat with serious implications for the child's chances for survival is reflected in the nature of hope, which is concrete and specific. The participants hope that medicine will provide a complete, definitive and immediate cure for the illness. Although no such cure presently exists, the parents have a profound belief that ongoing research in gene and stem cell therapies may produce a cure. This belief is fuelled by the excitement surrounding

technological developments in general and specifically by the advances made in characterizing the genetic basis of DMD. For example, participant 5 states that:

At the beginning, you kind of think 'Oh, this is down the road, this is 10 years down the road, this is 15 years down the road. They're going to find a cure; technology and medicine has come by leaps and bounds, when they started looking at gene therapy'. So, I think in the beginning we just said to ourselves 'Oh, this is going to work out'. In your head you say, 'Okay, they're going to find something, we're going to be delivered'.

The parents' hope for a cure helps them to sustain their aspirations for the child at a time when they perceive his future to be bleak. Concretely, the participants hope that their child will be able to resume his previous way of life and live again in the realm of normality as defined before the onset of the illness. The hope for normality for the child, for him to be like others, requires that an immediate and miraculous medical breakthrough take place. Participant 5 describes this by hoping that:

... they would find some kind of medicine and your [child] is going to get up and walk. Or we'll find some kind of cure, and not only will it stop the disease, but go back and erase all the damage already done.

Learning to Adapt

Context. The parents' cognitive appraisal of the illness evolves when they are forced to immerse themselves in their child's daily life. The parents are confronted on a day to day basis by new challenges associated with their child's illness; loss of mobility, increasing dependence and the appearance of new cognitive and behavioural changes. Parents as well as the child experience an increasing sense of social isolation. They feel different from others.

This isolation is evident when hearing the account of participant 2 recounting that his/her son 'doesn't move anymore, and my work friends say 'It's boring coming to your house. You're never there, and when you

are there, your [spouse] is gone'. We are losing our friends.'

As active caregivers, immersed in the day to day experience of caring for a child with chronic illness, the parents discover that they do possess the resources that allow them to care for their child.

During this period, parents become acutely aware of the physical limitations of their child and the progression of the illness. They grieve all of the losses associated with their child's illness and experience difficult emotions. Nevertheless, through these different grieving experiences, they develop their own sense of normality. They no longer live according to their norms preceding the diagnosis, but they redefine their sense of normality in accordance with their new reality.

Despite the negative emotions associated with this period, parents also experience a sense of personal achievement. The sources of this personal achievement stem from successfully overcoming the daily challenges associated with the care of the child, seeing concrete improvements in the child's health and sense of well-being, as well as successfully integrating the child's illness into the life of the family. For some parents, the sum of these significant achievements allows a unique personal transformation to take place. Participant 5 states that:

Once you're through that stage then you feel stronger inside. You feel more hopeful in your own abilities to move on, and you're not relying on others to make your life better, because that's not going to happen... At a certain point you start believing in yourself; 'I can do this. I can take care of this. With help, we're going to do alright'.

In summary, the parents' proximity to the experience of caring for their child transforms their perception of illness from that of a stranger, to the illness being a part of their child: outside but by their side.

Coping. As the illness progresses, the parents must learn how to meet the immediate needs of the child in order to promote his well-being. This learning process requires an

active involvement and the development of personal resources and abilities. In other words, the parents acquire and implement new coping strategies to address two different realms of their reality. The first pertains to their relationship with the child, and the second involves the adaptation to a new family dynamic and the relationship with the outside world.

More specifically, parents learn how to interact with their child in a way that will respond to his changing physical and emotional needs. Although this response varies from family to family, it usually entails acquiring abilities to provide the daily care and finding the necessary resources to maximize the child's comfort and autonomy.

The parents must also integrate the child's illness into the family dynamics. The family members, including siblings, learn to accept the limitations that the illness brings but also recognize the uniqueness of this experience as an opportunity of enrichment for the family. When referring to family life, participant 1 states that:

We try... and be as normal as any other family. He's part of the family and he has to be respected like everybody else. He gets a lot of support. He knows that, and the other siblings too know their part. They know the family routine. They respect J. and he respects them, and they help each other any way that they can. It's hard for the siblings too because sometimes I've got to spend more time with him than with them, but we try to make it work.

Finally, parents become more engaged with the community at large. They actively search for outside support, network, attend support groups, participate in fundraisers and interact with other families who are sharing the same experience. In parallel, they maintain an ongoing relationship with the medical team and continue to seek out information pertaining to recent advances in research and treatment.

The acquisition of the parents' new coping strategies means that the illness is no longer perceived as an outside threat but becomes incorporated into daily life. With the evolution of this cognitive appraisal and through

this new way of being, the family redefines their norms according to their reality.

Fabric of hope. The parents perceive the child's illness as part of their daily life. They must develop various abilities and coping strategies that are very practical in nature and address the pressing physical needs of the child. The parents must be active providers of care to their child. Their lived experience of hope reflects that context. The child's response to the parents' care becomes their hope. Indeed, the parents are able to hope because they see their child able to enjoy life because of their care. In other words, parents hope that their care will have a positive and tangible effect on their child's sense of well-being. Participant 5, the parent of a 16-year-old child with DMD, states that:

[My daughter] needs me so much . . . She must give me hope or I'd quit. When we go somewhere, do something special . . . I must feel for her that she's hopeful for her life or she wouldn't be happy, she wouldn't be doing the things she would be doing.

In summary, hope emerges from the parents' involvement and their sense of growing autonomy and becomes more reachable than a miracle. More specifically, it is part of the here and now; it is intertwined with their daily life. Hope is rooted in the actual experience of caring. In that sense, the lived experience of hope becomes more grounded in the reality of the child, the challenges arising from his illness and the adequacy of the response that must be provided by the parents.

Beyond the Illness

Context. As the illness progresses, the child is no longer able to walk independently and grows more and more dependant on others for the activities of daily living. Progressively, the illness becomes even more demanding for the parents. Despite the fact that more resources are required, the parents are not overwhelmed as they now have the confidence that they can meet the child's needs and the different challenges associated with the child's illness. There is more space for

reflection and a greater degree of serenity. Participant 11 describes the thoughts that ensued from a meeting attended with other boys suffering from DMD:

I guess the first thing you realize is they were people and the chair didn't define the person and they were an amazingly articulate, wonderful, funny, intelligent group of boys, and I thought 'Wow. If A. is like that when he's at that age, I don't care whether he's in a chair or not'.

The focus of the parents changes from being exclusively directed towards the physical implications of the illness to encompass the child's development as a person. Indeed, the child is less an infant and more a young adult with a sense of his own self-identity, who needs to relate and express his own individuality. The emergence of the child as an individual invites the parents to be more attentive to the needs associated with this period of human growth. The relationship between the child and parents evolves from being almost a one-way relationship where the parents are primarily caregivers to a more mutual relationship where the parents act as facilitators and educators in this process of growth.

This mutual relationship becomes evident through participant 7 who states 'Yes. We learn to love through him. We learn love. I give him unconditional love, and he shows us an aspect of life that we probably wouldn't have had had he not been here: how to love.'

The parents' perception of the illness continues to evolve. They now appraise it as an integral part of the identity of the child. In other words, the illness made their child the way he is. It is one of the constructs of their child's personality and individuality: a construct that they used to fear but now accept. In a way the illness adds a special value to their own human experience and to that of the child himself. The illness, previously a stranger, then present in everyday life, is now an aspect of the child's identity.

Coping. With this perception, the dominant coping mode is more cognitive in nature.

The learning process of the parents becomes more spiritual. More specifically, the parents give meaning to their entire experience of the child's illness. They are able to make the experience coherent and they give a legitimacy to it. The day to day life remains demanding but it is lived in a new climate of serenity. Participant 1 asserts that:

The only hope I can have is at a spiritual level. The only hope that gives me strength to take care of my son. That's the hope that I can go and get for my own strength, but also maybe for J's future that will certainly end with death...

Fabric of hope. At this point in the trajectory of the child's illness, the parents' perception has been transformed. They appraise the illness as a part of the identity of their child. In that context, coping is more cognitive in nature. The lived experience of hope reflects that evolution. Hope is deeply rooted in the child himself. His sense of self-identity and the emergence of his individuality as a human being become the very source of the parents' hope. When reflecting upon this experience, participant 3 describes that:

Your child hasn't really changed that much on the inside or in their personality or the way they were brought up... You're talking about the inside of the person, not the outside of the person. The shell isn't what makes the person, and the inside K. has basically been the same type of person all along... Of course, she's growing up, getting more mature... but that hasn't changed for us. Her being, the inside of her being has always been the same.

DISCUSSION

According to Cohen and Lazarus,⁷ the cognitive appraisal of the source of stress (i.e. the diagnosis) is central to the process of psychosocial adaptation to chronic illness. The current research findings suggest that hope emerges from this cognitive appraisal. The phenomenological analysis shows that participants perceived their child's illness in three different ways: as a loss, as a call to

cope and finally, as a spiritual and intangible experience that allowed them to rediscover their child. Through these different ways of perceiving the source of stress, emerges a hope that reflects that cognitive appraisal. More specifically, when the child's illness is perceived as a loss in the context of the crisis following the initial diagnosis, the parents hope for a quick solution that will fix the situation and bring them back to their life prior to the disclosure of the diagnosis.

With the manifestation of the child's initial symptoms, participants are forced to face reality and respond to the child's needs. From the illness' trajectory emerges a new perception. Participants appraise the illness as a call to adapt and to develop new abilities and find the necessary resources. Within this perception, a different fabric of hope appears. It is rooted in the actual experience of caring. Finally, nearing the end of the illness' trajectory, the participants no longer perceive the child exclusively as an ill person in constant need of care but as an individual with his own characteristics, allowing the development of a relationship where the parents and the young adult are able to relate. Therefore, the fabric of hope becomes much more spiritual in nature and is rooted in the child himself. These findings reveal the cognitive aspect of hope. In other words, the fabric of hope is in relation to how reality is appraised.

The theoretical approach developed by Cohen and Lazarus⁷ describes perception as a constant flux between reality and the individual. In other words, perception is a transactional and dynamic process. Since hope seems to emerge from participants' cognitive appraisal of their child's illness, hoping also appears to be dynamic. This finding is in line with what DuFault and Martocchio³⁷ suggest about hope: that it is 'a multidimensional dynamic life force'. What our research adds is that the dynamic aspect of hope is in relation with its essential source: perception or cognitive appraisal of reality.

Research, which has already been conducted on hope, shows that this

phenomenon is a goal-oriented positive orientation towards the future.¹²⁻¹⁶ Our research supports this hope construct. However, our findings also suggest that these goals could evolve depending on the changing perception of illness.

Indeed, immediately following the diagnosis, parental hope is concrete and specific. Parents hope for a medical breakthrough that will cure the child almost instantly. This goal emerges from the cognitive appraisal of what is happening. Parents are experiencing a crisis and their goal is to find an emergency exit that will bring them back to normality. With the appearance of the first symptoms, parents have to adapt and they perceive the child's illness in a different manner. Their goal, therefore, is to be able to develop the necessary abilities to meet their child's physical needs. Finally, at the end of the illness' trajectory, DMD loses its centrality in the parents' perception of reality. They went through a crisis, they adapted and now they face their child's mortality. Nearing life's end, parents perceive their child as a young adult with his own individuality. Parental hope undergoes a final transformation into, as was previously mentioned, a spiritual and intangible form. Parental goals consist of seeing their child becoming a developed individual in his own manner.

Research conducted on parental hope in the context of childhood or adolescent illness experience indicates that hope is an inner resource that can help sustain parents' efforts in caring for their ill child.^{30,31} Our research supports the notion that hope can function as an inner resource that is supporting parents, especially when they must develop new abilities to provide their child's daily care.

In summary, our research findings indicate that cognitive appraisal shapes the appearance of hope and gives it a highly individual and dynamic quality. This is why our description of the analysis pays special attention to the context and how this context is perceived by these parents. Associated to these specific perceived contexts are various

coping abilities and fabrics of hope. This is why it is important to situate hope in the specificity of an individual experience. The fabric of hope can be an indicator of how the experience is lived and appraised.

This research also shows the importance of hope in the context of psychosocial adaptation to chronic illness. It is undoubtedly a valuable inner resource that sustains this process, as Gelling¹³ describes. Our research findings, however, go beyond his conceptualization of hope. Without negating Gelling's¹³ point of view, our findings suggest that perception is the source of hope and gives it its colour and flavour. Our research points out the fact that we need to situate hope in a context and that it may not be a reality that stands alone and which can be isolated. Because perception precedes and gives shape to hope, healthcare professionals involved in the development of hope fostering/facilitating strategies need to recognize the centrality of the cognitive appraisal of the illness.

Despite this study's interesting findings, it must be considered in light of certain limitations. First, this research strived to understand and describe the experiences of hope in parents with a child living with DMD. As this is a very specific medical condition, with particular consequences (i.e. progressive disability and fatal outcome), findings may not be transferable to the context of patient hope or of parental hope with a child suffering from other critical and chronic illnesses. Second, although the inductive quality of phenomenological research allowed the perception aspect to emerge from the participants' experiences, further research is needed to specifically examine the phenomenon of hope in relation with perception.

ACKNOWLEDGEMENTS. This research was generously supported by grants from the CHEO Research Institute and the Faculty of Education, University of Ottawa. The authors wish to thank all of the parents who participated in the study and Monica Skillen

for her expert assistance in preparing the final manuscript.

REFERENCES

- Korf BR, Darras BT, Urion DK. Dystrophinopathies. Available at: <http://www.genetests.org> (accessed 22 October 2008).
- Giliberto F, Ferreira V, Dalamon V, Szijan I. Dystrophin deletions and cognitive impairment in Duchenne/Becker muscular dystrophy. *Neurol Res* 2004; **26**: 83–7.
- Polakoff RJ, Morton AA, Koch KD, Rios CM. The psychosocial and cognitive impact of Duchenne's muscular dystrophy. *Semin Pediatr Neurol* 1998; **5**: 116–23.
- Jacob P. Current approach to Duchenne muscular dystrophy. *Med North Am* 1989; **34**: 6301–3.
- Nereo NE, Fee RJ, Hinton VJ. Parental stress in mothers of boys with Duchenne muscular dystrophy. *J Pediatr Psychol* 2003; **28**: 473–84.
- Samson A, Siam H. Adapting to major chronic illness: a proposal for a comprehensive task-model approach. *Patient Educ Couns* 2008; **70**: 426–29.
- Cohen F, Lazarus RS. Coping with the stress of illness. In: Stone CG, Cohen F, Adler NE, eds. *Health psychology: a handbook*, San Francisco, CA: Jossey-Bass, 1979: 217–54.
- Moos RH, Tsu DV. *Coping with physical illness*, New York: Plenum Medical Company, 1977.
- Samson A, Siam H, Lavigne R. Psychosocial adaptation to chronic illness: description and illustration on an integrated task-based model. *Intervention* 2007; **127**: 16–28.
- Tomiak EM, Samson A, Miles SA, Choquette MC, Chakraborty PK, Jacob PJ. Gender-specific differences in the psychosocial adjustment of parents of a child with Duchenne Muscular Dystrophy (DMD): two points of view for a shared experience. *Qual Res J* 2007; **7**: 2–21.
- Kim DS, Kim HS, Schwartz-Barcott D, Zucker D. The nature of hope in hospitalized chronically ill patients. *Int J Nurs Stud* 2006; **43**: 547–56.
- Nekolaichuk CL, Jevne RF, Maguire TO. Structuring the meaning of hope in health and illness. *Soc Sci Med* 1999; **48**: 591–605.
- Gelling L. The role of hope for relatives of critically ill patients: a review of the literature. *Nurs Stand* 1999; **14**: 33–8.
- Wang C-e H. Developing a concept of hope from a human science perspective. *Nurs Sci Q* 2000; **13**: 248–51.
- Benzein E, Norberg A, Saveman B-I. The meaning of the lived experience of hope in patients with cancer in palliative home care. *Palliat Med* 2001; **15**: 117–26.
- Cutcliffe JR, Herth K. The concept of hope in nursing 1: its origins, background and nature. *Br J Nurs* 2002; **11**: 832–40.
- Farren CJ, Wilken CS, Popovich JM. Clinical assessment of hope. *Issues Ment Health* 1992; **13**: 129–38.
- Davidson PM, Dracup K, Phillips J, Daly J, Padilla G. Preparing for the worst while hoping for the best: the relevance of hope in the heart failure illness trajectory. *J Cardiovasc Nurs* 2007; **22**: 159–65.
- Yates P. Towards the reconceptualization of hope for patients with a diagnosis of cancer. *J Adv Nurs* 1993; **18**: 701–6.
- Little M, Sayers EJ. While there's life . . . hope and the experience of cancer. *Soc Sci Med* 2004; **59**: 1329–37.
- Clayton JM, Butow PN, Arnold RM, Tattersall MHN. Fostering coping and nurturing hope when discussing the future with terminally ill cancer patients with their caregivers. *Cancer* 2005; **103**: 1965–75.
- Elliott JA, Oliver IN. Hope and hoping in the talk of dying cancer patients. *Soc Sci Med* 2007; **64**: 138–49.
- Penson RT, Gu F, Harris S, et al. Hope. *Oncologist* 2007; **12**: 1105–13.
- Kylma J, Vehvilainen-Julkunen K, Lahdevirta J. Ethical considerations in a grounded theory study on the dynamics of hope in HIV-positive adults and their significant others. *Nurs Ethics* 1999; **6**: 224–39.
- Kylma J. Issues and Innovations in Nursing Practice. Dynamics of hope in adults living with HIV/AIDS: a substantive theory. *J Adv Nurs* 2005; **52**: 620–30.
- Herth KA, Cutcliffe JR. The concept of hope in nursing 3: hope and palliative care nursing. *Br J Nurs* 2002; **11**: 977–83.
- Feudtner C. Hope and the prospects of healing at the end of life. *J Altern Complementary Med* 2005; **11**: S23–S30.
- Fanos JH, Gelinus DF, Foster RS, Postone N, Miller RG. Hope in palliative care: from narcissism to self-transcendence in amyotrophic lateral sclerosis. *J Palliat Med* 2008; **11**: 470–5.
- Kylma J, Juvakka T. Hope in parents of adolescents with cancer- factors endangering and engendering parental hope. *Eur J Oncol Nurs* 2007; **11**: 262–71.
- Larson E. Reframing the meaning of disability to families: the embrace of paradox. *Soc Sci Med* 1998; **47**: 865–75.
- Padencheri S, Russell PSS. Challenging behaviours among children with intellectual disability: the hope busters? *J Learn Disabil* 2002; **6**: 253–61.
- Kirpalani HM, Parkin PC, Willan AR, et al. Quality of life in spina bifida: importance of parental hope. *Arch Dis Childhood* 2000; **83**: 293–7.

33. Eapen V, Revesz T. Psychosocial correlates of paediatric cancer in the United Arab Emirates. *Support Care Cancer* 2003; **11**: 185–9.
34. Husserl E. *Idées directrices pour une phénoménologie*, Paris: Gallimard, 1950.
35. Giorgi A. De la méthode phénoménologique utilisée comme mode de recherche qualitative en sciences humaines: théorie, pratique et évaluation. In: Poupart J, Deslauries JP, Groulx LH, Laperrrière A, Mayer R, Pires A, eds. *La recherche qualitative*, Montréal: Gaetan Morin éditeur, 1997: 341–63.
36. Karlsson G. *Psychological qualitative research from a phenomenological perspective*, Stockholm: Almqvist & Wiksell International, 1993.
37. Dufault K, Martocchio B. Hope: its spheres and dimensions. *Nurs Clin North Am* 1985; **20**: 379–91.

APPENDIX

I would like to ask you some questions. Please note that there are no right or wrong answers. Take as much time as you need, and answer as spontaneously as you can.

- (1) When you were first given the diagnosis of Duchenne muscular dystrophy for your child, what was your first reaction? (In the first few days? In the first month?) You may wish to talk about your feelings, your relationships, the way you saw your child and the future.
- (2) At the time of the diagnosis, could you describe, what hope meant for you? What were you hoping for your child?
- (3) And today, what does hope mean for you? What are your hopes for your child?
- (4) Why has it changed for you?
- (5) Could you describe for me one or two events, or a moment, or an experience, or receiving news, that was for you, a source of hope?
- (6) Over the progression of the illness, could you identify what has given you hope?
- (7) Does your child contribute to your hope, and if so, how? Please describe.
- (8) Within your family, do you talk about hope? (If so, please describe. If not, why not?)
- (9) Do you have anything else that you would like to add that we did not cover?