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► **To cite this version:**

Alison Edgley, Martina Sykorova, Elodie Stasi, Roberto Bartoletti, Dario Roccatello, et al.. “I Cry. I Simply Cry.” An Ethnography of a Lymphedema Summer Camp. *Lymphatic Research and Biology*, 2021, 19 (5), pp.479-487. 10.1089/lrb.2021.0058 . hal-03884712

HAL Id: hal-03884712

<https://hal.umontpellier.fr/hal-03884712v1>

Submitted on 5 Dec 2022

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“I Cry. I Simply Cry.” An Ethnography of a Lymphedema Summer Camp

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Abstract

Background: The aim of this study was to explore how self-management is taught, learnt, and experienced during a 3-day educational Lymphedema Camp for parents of children with lymphedema.

Methods: Participants (professionals, parents, and children) were observed during camp activities and interviewed informally and formally in focus groups. The embodied nature of the experience expressed by professionals, parents, and researchers became the analytical focus for understanding the felt tensions in the teaching and learning of self-management to families.

Findings: The affective sensibilities associated with the uncertainties involved in teaching and learning self-management skills were palpable given that: young people are now expected to take up strict time-consuming self-management regimens (often via the support of a parent) where “evidence-based” outcomes are uncertain or may not match the outcomes wanted by a young person (varying in age and therefore ability or willingness to engage); or where there are tensions within the family; and the variety of different professionals involved means that techniques varied but where these professionals also lacked the necessary skills training to guide them in *how* to teach self-management. An analytical focus on the distress, doubt, fear, loneliness, guilt, and moralism felt by professionals, parents, and the researchers supports us to identify the character of the problems associated with performing best practice care guidance where there is a lack of practical support or resources for *how* self-management in this population should be achieved.

Conclusion: To avoid these issues more training and research are needed on “how” to self-manage and stop victim-blaming that generates tensions and drives a wedge between the carer and the cared-for. When systemic problems get located with individuals (professionals, parents, or children), this directs our attention and understanding away from systems of care that lack coordination, may be under-resourced, and where effective training is absent.

Keywords: therapeutic children’s camps, chronic distress, doubt, fears, loneliness, guilt, moralism, emotional labor

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Introduction

LYMPHEDEMA IS A chronic and complex condition and is considered a rare disease when it occurs in children and adolescents. The cause of primary lymphedema in children is complex and is a result of a defect in the way in which the lymphatic circulation has developed.¹ In about a third of children, the genetic cause has been described although this is a rapid area of development. Very little is known about the profile in those affected with secondary lymphedema, which results from damage to the lymphatics in conditions such as cancer and other long-term conditions such as spina bifida.

Currently there is no cure, and so treatment involves combined forms of management: compression with bandages or stockings; manually applied lymphatic drainage techniques; skin care with creams to keep the skin soft and flexible; and exercise or at least keeping mobile.² Evidence for these various forms of management is far from conclusive and because there is no cure, what counts as evidence for a successful outcome of management is to look for evidence that edema is stable, and so, outcomes are measured physiologically: that the lymphedema has not spread; that cellulitis does not develop; and that the affected limb reduces in size.

In terms of the relationship between management and outcome, evidence does suggest that intensive episodes of professionally applied complex decongestive therapy (CDT) do reduce swelling,³ however, when measured longitudinally once intensive treatment stops, swelling is likely to return. Evidence for compression using bandaging and skin care to maintain skin integrity also rests upon the daily maintenance regimens of the body.⁴ Similarly, exercise has an evidence base in the sense that it is associated with keeping symptoms stable,⁵ however, as with CDT, bandaging, and skin care, it is sustaining the intervention that appears to be associated with the established physiological outcome measures.

As the evidence base for these forms of management grows, our understanding that it is the ability to sustain an intervention that is vital, care and management of lymphedema have increasingly focused upon self-management. If the critical factor associated with “good” outcomes (that do not include cure) is sustained care, then teaching patients to self-care is the logical corollary. What and how self-management should be achieved is less clear.

A systematic review of activities or treatments that patients used in lymphedema self-management was undertaken using Orem’s Self-Care Deficit Theory.⁶ The review concludes that self-management does not include professionally delivered treatment, and that control of swelling is only one outcome, with control of pain, heaviness, and maintenance of function, and the ability to have a normal life of high importance. However, the review concludes that there is little evidence to define the most useful methods to self-manage lymphedema due to the paucity of research.

Nevertheless, the International Society of Lymphology (ISL) and the International Lymphedema Framework (ILF) have both produced documents with the latest update from ISL appearing in 2020.^{4,7} In the latter, best practice was developed using mixed methods beginning with systematic reviews of the contemporaneous evidence and then an explicit consensus methodology. In the former, the explicit methodology is not defined, but it is based upon an international consensus. Both recommend individualized patient

care and both stress the importance of patient adherence to self-management supported by a professionally derived program of patient education. The ILF document includes a set of service standards for professional practice. The second standard focuses on empowering those at risk of or suffering from lymphedema.

While recommendations about psychosocial difficulties associated with the condition are included in the recommendations for assessment and management, they are contextualized within the medical model, which places emphasis on the early identification of mental health difficulties such as depression and anxiety. By framing mental health difficulties of life with lymphedema as primarily a barrier to adherence, the lived experience associated with the very real negative psychosocial effects of living with lymphedema, let alone strict adherence to a regimen of self-care, get framed as just more symptoms to treat. Sustained mental health difficulties may get reconstructed as non-compliance arguably driving a wedge between the prescribed goals of a professional and a patient’s proscribed sense of feeling cared for or about.

It has been acknowledged that standards of lymphedema care across the globe vary widely with many having little or no access to diagnosis or treatment coupled with a lack of agreement over what constitutes expert care provision within specialist services. This situation forces some families with children to seek treatment abroad. While the rationale for these disparities in service provision remains poorly understood, research has shown that the low profile and poor perceived social capital associated with having lymphedema may be an under recognized issue.⁸

In many countries, medical interest in the specialty is low and care provision has been devolved to nursing and other allied health professional groups who are known to have less influence over decision making and allocation of resources within complex health care systems.^{9,10} It is also likely that the wider cultural context in which someone with lymphedema lives will shape the experiences of managing this chronic condition. In particular actual and felt stigma, and cultural attitudes toward Cinderella conditions.¹¹

While the ILF deployed a consensus methodology that included lymphedema patients about *what* constitutes best practice, little guidance is given to *how* professionals should engage with patients. Self-efficacy and self-management are yet to be effectively conceptualized, let alone operationalized, although preliminary work in this area has begun.¹² The larger question, however, remains: how should we teach someone to adhere to strict, relentless, and time-consuming therapies, especially when cure cannot be promised and prognosis is indeterminate? A corollary and perhaps unstated question might query whether we can actually teach *all* patients to self-care?

Humans are psychosocially complex creatures and we know that some patients resist care, even if we (care providers) perceive it to be in their best interests.¹³ This may be because we have not found the best way to teach or it may be that some people are inherently unteachable on some things leaving the question of what care might look like, for such groups, more open. When the patient is a child or teenager who will inevitably rely upon parental (often the mother) input as part of a “supported self-management” regimen, these challenges are then magnified.¹⁴

Children, especially infants and very young children, cannot self-manage alone but depend on parents and caregivers for some or all their care. Meanwhile, teenagers are in that complex and often conflictual phase of seeking independence, while not necessarily having the recommended psychosocial let alone economic resources to become independent. While research strongly supports the need for an individualized approach to management, which engages the young person and family and also takes account of the child's age and stage of emotional and cognitive development (let alone complex family dynamics), how this happens is less well understood.

We do know, however, that in circumstances where care involves patient adherence, it is essential that understanding care needs from the perspective of the cared-for must be central. When the patient is embedded within a family structure, this is not straightforward, because as we know children's views may differ significantly over time from that of their family, particularly during adolescence. The problems of domesticating and integrating the best practice care regimens within the context of family life therefore are multifaceted and currently are little understood or researched.

To explore this question of how self-management is taught and received, the team undertook an ethnography of an educational holiday camp held in Turin, Italy (2017), for children with lymphedema and their families. These camps have evolved from an expert center in Montpellier, France, over the last decade. The model has been replicated nationally and internationally.¹⁵

Methodology and Methods

Ethnography is a methodology that places emphasis on collecting a range of data that will include observations of what people do, as well as listening (formally and informally) to what people say and think about what they do. It may also include collection and analysis of statistics, as well as documentary analysis of policy or other documents associated with the field of interest. Ethnographies seek rich, thick, and triangulated contextual descriptions and analysis of areas of social life that are complex and so resist positivist assumptions.

Ethnographies are interpretive and rest upon the ontological assumption that social meaning-making is epistemologically relevant to our understanding of social phenomena that are complex by virtue of the fact that they involve both physiological and social features of being human. Lymphedema is a physiological condition, but it occurs in a socially situated body. While positivist methodologies that predominate in medicine can tell us what might help a body heal or maintain itself, when therapies require the engagement (or even self-management) of a socially situated being, positivist approaches are less reliable for helping us understand the complexity of such social interventions.

Rigorous ethnography is judged by three key criteria: authenticity, plausibility, and criticality. The distinguishing feature of ethnography is the immersion through participant observation within the field of study. Authenticity is established by ensuring transparency of study design. Such transparency invites reflexivity on the part of the researchers, through which each stage of the study design is recognized as analytical and interpretive moments that are open to scrutiny.

The researchers must also interrogate the data to challenge any emerging theoretical explanation to avoid a ten-

dency for data to be homogenized or flattened. Plausibility requires the drawing together of a coherent narrative, which provides explanations about the local phenomena, making sense to those who participate in the research, and acknowledges that different interpretations of the same data are possible. Criticality invites the researchers to systematically and reflexively explore taken for granted assumptions (including their own) that emerge during the research.

The Methods

Our ethnography took place at a therapeutic camp in Turin (summer of 2017) to help families and their children learn how to look after their lymphedema. We received ethical approval from The University of Nottingham Ethics Committee. Written informed consent was obtained from all participants in this study, which included parental consent on behalf of younger children, who were also asked to provide verbal assent to inclusion.

The ideas for this camp derived from the French model of integrating learning with fun for young people and their families. A further element was that it was designed to be a break for parents. The program for the camp was coproduced between professionals and a parent group (both international). It was also supported by the ILF. We were together for 3 days and we all ate together and professionals were informally available throughout. Each family, the professionals, and the researchers had their own cabin, and these were situated around the edge of the camp. Siblings were also invited. Our days were structured with morning sessions, which were a mixture of running focus groups and practical workshops to teach and learn self-care techniques. On the first morning, we invited children and adolescents to draw pictures of themselves, and their experience of living with lymphedema.

We also gave all the children cameras, so that they could take photographs (analysis of these images is in a separate article).¹⁶ The afternoon was family time, when there was an opportunity to use the facilities. These facilities included a swimming pool; aqua-aerobic classes (run by therapists for the children); a room to play table tennis; a high-rise climbing facility; and space to play football. We had a dragon-boat trip and a party on the last evening. At this event, each child was given a balloon, and was invited to put a wish into the balloon and then release it. The facilities at the camp are very beautiful, with a river running alongside the camp. The weather was sunny and warm, although there were mosquitoes (which for children at risk of cellulitis provoked considerable concern).

We ran 2 focus groups each morning, one for professionals and one for parents. These were organized by language (English, Italian, and French) and we had simultaneous translation with headsets. There were 14 professionals and 26 parents. Also invited to the camp was a voluntary peer mentor: a young woman with lymphedema who fully embraces the self-care regimens and who regularly attends these camps to inspire and encourage young people.

While children were also part of the research, and the findings from an analysis of their drawings and photographs were reported separately,¹⁶ we nevertheless bring in here relevant findings from this element of the study, where they support the broader ethnographic findings.

Data were collected by C.M. and A.A. Two research students were also in attendance and formed part of the

team, but they did not formally collect data. Observations took place each day, outside the focus groups. C.M., A.A., and the two research students ate with the participants and professionals and watched camp activities. They also organized and supported the collection of pictorial data from the children. Observations were not formally recorded during the time, although C.M. and A.A. had daily briefing meetings that were informally recorded. Observational data were formally recorded retrospectively.

The findings presented here are drawn from all elements of the data collected. While in other articles we have identified which language focus group a quote derives, here we have chosen not to identify the data in this way. This is because, arguably, the data presented here are emotionally sensitive and we did not want those participating to be able to recognize one another, thus ensuring anonymity. Where we present clusters of data to evidence a point, we have ensured that the theme explored is identifiable across the different language group categories.

Analytically we coded each data systematically and then drew themes from across the range of data sets. A striking feature of difference between the formal verbal data and the observational data was that while the verbal interview data interviews point to explanations of distress (among parents and professionals), the observational data are saturated with reflexively felt records of earthy visceral forms of distress. This weight and intensity of the distress, its very embodiment became our analytical lens.

Findings

The overwhelming finding from the range of ethnographic data was the level of expressed emotional pain among the parents, and in some cases among the professionals as well as the research team. Feelings and emotions are felt within bodies (embodied), and it was clear that it is not only children with lymphedema for whom the embodied experience is relevant when it comes to care and self-management. Bodies are “simultaneously physical and affective, social and individual, produced and producing, reproductive and innovative.”¹⁷⁽¹¹⁶⁾ This dialectic was integral within the verbal accounts and the observations. Bodies are marked and etched from within a social and political context, and how we learn and internalize cultural rules and norms is a felt experience.¹⁸ The affective struggle to both enact and train self-management was unmistakable. Historically, Western philosophy has treated feeling and the body as unreliable sources of bias, things to bracket. Deleuze and Guattari¹⁹ and Merleau-Ponty²⁰ resit the mind/body split and show us the value of putting sensory affect alongside “talk” and discourse to inform our “knowing.”

Throughout the camp during the day and in the evening, parents could be seen crying as they talked with other parents or with professionals. The emotional toll for parents who love and care for their child with lymphedema, an uncommon disease (even to some health professionals) that carries so much uncertainty, was palpable. Feelings included fear about caring for, the trajectory of the disease, and a child’s future; guilt at not understanding or assuming responsibility for the disease’s etiology; anxiety about the pressure of a time-consuming and difficult self-management regimen with contestable efficacy; all while feeling alone as a parent of a child with lymphedema.

My child was diagnosed with Lymphedema and it was our first child and I didn’t know anything about this disease and I was really in shock and I thought that she would die. ... [W]hen I found out it could not be cured that was the worst of it.

... when X turns 18 all my links will be gone, he will be in the adult section which I have heard is quite different to paediatrics which is another concern, a massive concern right now. Somebody’s got to know your child and to understand them, someone I can trust.

I feel so much guilt and I think we all do the same. How did this happen, why to us?

I am doing the bandaging every night even though we don’t see any difference.

[What makes you keep going?] You have to keep going. ... it’s lonely, there are no other parents really to talk to.

Parents could be seen in the camp struggling with their feelings as they interacted with one another, as they interacted with their children and between parents within a family unit. At times it seemed as though families and individuals were falling apart in front of our eyes. Having a psychologist on the team felt essential in order that we might sensitively and ethically navigate the research space. (One notable challenge was that A.A. was approached for psychological support. She had to explain that she was there in a research rather than therapeutic capacity, and yet her therapeutic skills were integral to the data collection process.) Our sense of what we were seeing was that the research process, which included asking parents how they felt and experienced self-management and care for a child with lymphedema, gave them permission, perhaps for the first time, to fully express the depth of feelings as well as the struggle of their experience. To feel heard and acknowledged for their struggle seemed an immense relief and release:

We need to vent our stress, we need to release.

While sadness and pain were anticipated, the visceral embodied experience of the suffering was not. At times the team’s own embodied experience of witnessing the suffering left us with many ethical dilemmas not least of which was fear that what had been unleashed risked leaving participants “too” raw and vulnerable. The team undertook to check-in with distressed parents (both during and also after the camp) to be sure participants were not being left entirely alone with their surfaced feelings.

While the depth of pain and grief felt, at times, to be overwhelming, much laughter and pleasure among parents were also observed. As they sought to learn self-management techniques and support one another, the bonding in their common experience was appreciable.

It is good to share with others, people in the UK, in Italy, we are the same we share the same feelings of sadness and guilt but we can encourage each other and it helps us, we can have the opportunity to listen, to speak up and to ask questions.

In this camp we really feel normal. Because we do everything, we have fun, swimming pool, football, climbing, adventure park. It is beautiful and we have fun. ... Thank you from the heart to the personnel of the camp. We have been united and we can learn more about our condition.

The framing by this parent, "our condition," tells us that lymphedema is not just felt in the body of the sufferer. Parents too have lymphedema experience in their body, especially as they shoulder the responsibility for promoting self-management.

Watching children and parents practice new self-management skills in a supported environment, with experienced practitioners on hand, the sense of camaraderie was strong. Observations of parents and children eating and drinking together as well as participating in the camp's activities meant the camp's backdrop as a fun break and a holiday for hard pressed families raised additional discomfort among the research team. Even though all participants had consented to being involved in the research, the families had been invited to an all-expenses-paid activity camp, for a holiday and a break with the promise of educational input about self-management. This backdrop generated an uneasy juxtaposition for the research team given the poignancy of a parent's anguish raised by the additional exposure to the research team and their questions.

Aside from these informal observations, crying was also recorded during the focus groups. The rawness within these again felt so strong that at times the researchers had to consider whether it was ethical to continue. However, when participants were asked whether the focus group should stop, participants vehemently rejected the idea. While some parents reported in the focus groups that their children also become emotionally distressed about their condition, such emotions were not evident during the camp. The children, by contrast, just threw themselves into the fun and joy of the activities on offer. Where there was an exception to seeing children having fun, there were some siblings who were observed sitting on the outside, quietly and with much less engagement in the collective experience.

For some parents watching their children participate in camp activities was observed to be extremely stressful. Parents were seen wrestling with their feelings of fear for their children, should the physicality of the activities risk a child hurting himself or herself. Given the very real concern that broken skin may become infected and become life-threatening, the emotional challenge of seeing their child climb walls or the high wire, play football, swim, or engage in rough and tumble was for some parents overwhelming.

Parents were also observed seeking out individualized information or guidance from the professionals while they had them at the camp. There was a strong sense of emotional pressure to glean more, better information to better support their parental care. The juxtaposition of the camp's focus on the self-management *regimens* of care together with the physical freedom being encouraged did not always sit easily with parents:

... we are afraid, we are afraid of infection and that happened last night and we had to go to the doctor and he is now on antibiotics from last night—we cannot solve this problem ourselves.

Here we see that while the framing of care is self-management, parents fear this may mean being left alone without professional support, and this feels especially hard when the advice from different professionals is contradictory. Parents were seen arguing with one another and their child.

It is not easy as they are "teenagers." She is very stubborn.

I'm afraid it could go into the arms and then it would be both legs, arms and I was told not to do football by the hospital.

And yet for many the opportunity for their children to feel like a "normal" child was keenly felt.

... about the benefits of the camp, my daughter has been really positive, just to play with other children, to not stand out, to be the same, it is wonderful.

Most children were seen fully embracing the opportunities offered by the camp and could be seen exuberantly enjoying themselves. While in some cases their drawing (where they were invited to draw themselves) made reference to their lymphedema, for most this appeared "matter of fact" or was absent in what they drew.¹⁶

While being among other families with children with lymphedema was interpreted as cathartic, some parents were observed finding the potential challenge to "their" regimens of care at home extremely difficult, because children were being exposed to "other" ways of doing things from other families. Parents and children were being encouraged to recognize that it is possible to sometimes skip aspects of the self-care regimen, without dire consequences, and for some this was difficult, for others it was recognizably a relief.

X has just started to tell me not to bother him so maybe I should listen to you and just back off?

Yet, educational advice and guidance places a rigidity around regimes of self-care, a care that is invasive on family time. As one parent observes:

you have to wear your bandages every day and you have to roll up the bandages, it's a core task that needs doing every day and it is time consuming [original emphasis].

Aside from the depth of feeling voiced and expressed by parents, the embodied experience among professionals of working with children with lymphedema was also tangible. The professionals ran daily sessions to teach parents and children techniques to achieve self-management. The focus of these sessions was on how to do the bandaging and how to self-massage, and teaching standardized techniques. Observation of their preparation for these sessions suggested there was considerable discomfort between them about what and how to teach, because there was little agreement (or guidance) about what and how to teach self-management.

I am a physio ... My therapy is all based around getting the kid moving.

my focus really is to empower and everything I do really is to empower the client or the mother if they are children.

I have a totally different point of view, maybe because I am a doctor, the main thing I think about with self-management is ... how will they be able to use the equipment?

Teaching the very basics, that it what it is all about, education.

What self-management means and what counts as a successful outcome is also variously understood:

Good self-management is somebody who doesn't need me, doesn't come and see me in hospital, manages to do sport, attends school regularly and has a social life with friends. That's what it means to me.

Is it part of self-management when they need to come back?

... the volume is important to us and we like to be strict with this. We don't want the volume to significantly change, we have numbers and a protocol that we like for them to meet.

I think [they should] ask for more help, to be almost less, not to be so self-efficient that actually they create a problem.

I know I can get him to another 20% volume reduction but will that get him into jeans? No. Does it keep him safe from cellulitis? Maybe. Does it placate his mother? Yes. Can we tell him to swim and walk and cream? Yes. Are we successful? We are not sure.

There was a recognition among professionals that their training may have included what lymphedema treatments are available, but not necessarily *how* to make self-management an achievable outcome or the psychosocial training that may support this:

I think of the 160 hours therapy training ... there is no self-management in there.

I am 25 years a nurse ... so in the modules I did, we talked about exercise but really, really do we know what we are giving the clients?

... in my teaching I include almost on a level of CBT the concept that the client must be self-managing.

The framing of this last quote, where "almost" frames a perceived skill need is then put together with a "must" about an outcome, speaks volumes about the tension professionals feel. Some professionals had a more performative self-confidence than others, but even among those working in larger teams, there was a sense and an expression of loneliness about the affective difficulty of caring for these young patients.

I try to do my best and I ask a lot to myself. Sometimes I cannot cope with it and I worry if I did the right thing or not. At the end I mean well. Even if I got it wrong and did a mistake I did my best. I feel lonely.

Perhaps the sense of isolation is unsurprising given that they comprised a range of professional groups and they were from three different countries. However, the challenges were not just about their professional and geographic differences. The effect on professionals of working with the nebulous nature of best practice, coupled with the complexities (or perhaps futility in some cases) of gaining adherence for self-management, could be felt by the research team. The struggle, anxiety, sadness, and sense of impotence observed among professionals was compounded by knowing some families lack resources, cannot be helped in the ways families want to be helped, or professionals recognize that the neo-liberalization of services means the tangible difference they could make is being cut back:

I feel sort of frustrated and hopeless in conversations with parents who have difficulties in their financial situation, but we always try and find something we can do. I feel sad, it makes me sad when I am not able to find a solution because we are really willing to help these children and if it doesn't help, it makes me sad.

I have to say in [X country] if I am honest, self-management has been used because of diminishing resources.

Just as with parents, professionals too were seen crying. For professionals, the patient is the child, but they must mediate the goal of self-care with the family and usually the mother. In some cases, the feelings of care for the patient coupled with a sense of professional impotence around complex family dynamics left professionals with feelings that were difficult to reconcile.

In our work as physiotherapist, I touch the patients, so I come close to them both physically and also with their feelings. So, after a while we build a loving link with them. Nearly always with the children. ... My emotions also come out more easily with children. When this affectionate bond is created, I also feel responsible. As if they were my children.

Mediating care needs through a parent was described as far from straightforward at times, especially if the parent is struggling:

... I have one hour that I know I have this leg to deal with and I understand that it is [the mother] that needs most support ... but where do I go with this? I am his therapist ... I can't take [mother] and sit for 40 minutes and ask her what can we do to help you? I have 8 more patients to see.

Aside from the problems of mediated care and education, children themselves go through many phases, and so for a professional to know how to interact with and gain the trust of children of varying ages requires specialist understanding that may not be available in coordinated ways:

We talked to some paediatricians specialised in rare diseases and we were told that it can help if the teenager or child is allowed to experiment themselves when they have problems. This can be a compromise, and this also releases a bit of my sense of responsibility. So the aim is not to scare them. The children see the consequences of their action or non-action.

The tensions within the professional role and their best practice remit for patients to self-care were most keenly exposed when the focus group discussion turned to the criteria for selecting families to attend the camp. Families who are able to adhere to self-care were seen and treated as "success cases" worthy of professional attention and suitable as role models:

We considered the children who could come to participate and chose the ones that we felt would benefit most from the camp, the ones who were ready to respond and comply.

No we chose the ones that replied, that wanted to come ...
 We think about who might get the most out of it, who is able to give back also.
 No... I did reject a family. ... She had to be hospitalised twice because she was not compliant with the treatment she had to go through, and we had suggested a social worker and a psychologist, and she refused.

The tacit and at times the explicit language of compliance, mirrored yet framed unproblematically in criteria for "best practice," leave professionals vulnerable. Where the challenges associated with achieving compliance go unacknowledged and under-resourced, professionals with experience of noncompliant families (where the reasons for this are myriad), distressingly describe how they may wrestle with and come to feel about their own capacities as professional practitioners:

I went to the bathroom and looked in the mirror and I said, he is YOUR patient for the next hour, find a way, find a way to just do this, you feel a failure, ... there is this competitive side of myself, that is ego driven: when you see a volume decrease from 9 litres to 3 you say fantastic work, well done you, look at you, you know how hard you have worked. If patients are not self-sufficient, you see your working practice as a failure

If adherence to self-management gets framed within best practice guidelines as a series of unproblematic steps (focusing only on *what* rather than on *how*), then "failures" too easily get framed as the responsibility of someone. Where professionals were not blaming themselves, they were also seen transferring blame to the patient. In a complex emotional shift from a personal sense of failure, some professionals could be seen rationalizing and shifting blame onto families:

We have two kinds of patients. One is relying solely on the health care system and wait for treatment. In my opinion one should be more responsible and not delegate to others what they can do themselves. For the long term project we are trying to encourage the patients to be more self-sufficient and not rely on the system too ... so much.

Just as what to teach in the camp's educational sessions was observed to be unclear to the professionals, so doubt became enmeshed with fear. Fear of (professional) failure generated by doubt threaded its way through all three focus groups with professionals:

... one patient ... who has a problem with the arm and came here last year and I have seen her again recently, but her arm has gotten worse and I got scared. It is a teenager. It might be linked to her age. She does not do anything. They (parents) bought her the pneumatic compression machine. She could swim in the pool because she has a pool. But what did we do wrong? Where was the mistake? Maybe she is afraid? How am I supposed to go on about it? We want her to know

that we want her to improve and not get worse. Perhaps I am too friendly? Perhaps I should be more authoritative ...?

The silence in best practice guidelines about *how* to engage, not just patients but more problematically parents of children in self-management as well, could be seen generating accounts of *ad hoc* ideas and practices of care. Some successful, some not. The lack of effective joined-up support for professional practice is palpable in the accounts of professionals.

The ensuing uncertainty and distress in both professionals and parents were keenly felt and could be seen sitting between and shaping relationships between parents and professionals. The feelings are the "elephant in the room" or the "canary in the coal mine." They alert us to problems that sit within formalized interactions where resources are scarce or ineffectively distributed, where power differentials abound and where honest effective avenues of feedback are not encouraged. What was notable by its absence is parents "blaming" professionals. While professionals who had failed to effectively diagnose the child's condition came in for criticism, professionals with expertise in lymphedema were either not openly judged or were seen in appreciative terms.

Parents at the camp were grateful parents, grateful for the professional attention, grateful not to be wholly alone with the enormity of the circumstances facing them. Parents who despite the rigors, uncertainty, and fear associated with self-care remained willing to do their best under the terms offered to them. An emotion not identified, but one closely associated with fear and grief was anger. Absent were the angry voices, the voices of parents or young people unable to tolerate the uncertain correlation between best practice regimens of self-care and outcomes that a young person might aspire to. Absent were the family voices unable to make strict regimens of self-care of children work where adult relationships are unstable or where the struggles of making an income or running a home overwhelm a family. The tacit selection criteria of families that are willing and able to adhere meant the voices of families unwilling or unable to be a role model for others were absent.

Discussion and Conclusion

The avalanche of feeling unearthed by the findings among both parents and professionals within this ethnographic study speaks to the fragility of the relationship between professionals and parent and within families where doubt and fear pervade. The findings illuminate the deep underacknowledged but keenly felt tensions at play where best practice guidelines do not effectively guide resources and understanding toward *how* best practice might be achieved. Leaving the responsibility for operationalizing best practice with individual professionals (who are not themselves homogenous in training), our attention gets diverted away from systems of care that lack coordination, may be under-resourced in terms of time and emphasis, as well as the failure to adequately train professionals in the psychosocial skills associated with care in its broadest sense.

The "feeling rules" associated with professional practice leave professionals engaged in forms of emotional labor, where they must "surface act" with parents.²¹ Their own

doubts and fears about what and how they practice are not permitted. Parent's doubts and fears meanwhile are not encouraged, because focus must remain on best practice guidelines, as though congruence between parties must be achievable. Such unspoken tensions risk and do disfigure this relationship. Families for whom the logic of the care provided is insufficiently evidenced-based within their experience, or where the goal differs from that proscribed by practice or where the struggle of daily living makes adherence untenable risk being labeled by professionals as deviants in ways that could be self-fulfilling.²²

The stigmatization of "noncompliant" families by the care system leaves families and children who are already socially stigmatized by a condition that visibly disfigures, doubly discriminated against. While transferring blame from the professional to the parent or patient may ease the felt tensions within a professional, it does little to advance our understanding or nuance our practice.

The lens of embodiment invites us to honor feelings as more than illustrative of the subjective, personal, and thus private experience. The social flows through our bodies, but is not reducible to the psychological, the personal, or the individual. As Ahmed argues, "feelings might be how structures get under our skin."²³(p.216) Unpalatable, unwanted antisocial feelings (fear, anger, sadness, depression) were found in patterned ways within our data sets, and we argue that they usefully inform us of what needs more of our attention or perhaps a redirection of our attention and a questioning of our assumptions. Feelings are more than things to pejoratively label, ignore, or fix in ourselves or others. They offer a wealth of information, they point to distress and thus gaps in our professional and academic understanding: blind-spots, hubris, complacency, and selective attention.

The individualization of responsibility for success of self-care places emphasis and attention on players who function within systems and regimens of "care" that are desensitized to the full experiential costs of living within a family where a child has a poorly understood, under-resourced, life-limiting condition. Professionals may be highly experienced in working with a condition, but this is not the same as living with it. The fear associated with professional failure is real (and should be taken seriously), but it is not the same fear as the daily parental fear of being unable or uncertain how to effectively protect and support an ailing or vulnerable child.

As Djulbegovic and Guyatt²⁴ argue in the *Lancet* evidence-based practice and so-called hierarchies of evidence risk being hollow and even faulty, where they do not also take into account the values and preferences of the patient. Values and preferences are felt. As professionals we do not only learn to think in terms of hierarchies of evidence, but also hierarchies between professionals where the voices of some professionals are thereby assumed to hold more weight. Adherence to self-management of care in children shows us that this is a multiprofessional concern and that no one professional group is better equipped than any other. There are many gaps, and we need to question some of our starting assumptions. We may not initially know how to integrate a patient's values and preferences (even those we do not agree with), but we need to humbly begin the dialogue and place value on forms of evidence and one another that may feel counterintuitive to some of the assumptions built into our professional training.

Finally, while the lymphedema camps are clearly a valued resource for many families, and a place where children with lymphedema, perhaps for the first time, can feel "normal" by dint of being among other children with the same condition doing "normal" things children like to do was powerful, our research suggests that camps are not only an educational fun experience. The depth of feeling associated for everyone involved suggests that the selection process and running of these camps need to be sensitively handled and we would argue would benefit from the addition of professional psychosocial support.

Author Disclosure Statement

No competing financial interests exist.

Funding Information

Funding for the children's summer camp was obtained from a number of sources, however, no funding was obtained to conduct and analyze the ethnographic study.

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