

## ORIGINAL RESEARCH

## The Hidden Impact of Molluscum Contagiosum: A Survey of Caregivers' Experiences with Diagnosis, Treatment, and Impact on Quality of Life

Pearl Kwong MD, PhD<sup>1</sup>, Adelaide A. Hebert MD<sup>2</sup>, Collette Utley DNP, NP-C<sup>3</sup>, Melissa Olivadoti PhD<sup>4</sup>

<sup>1</sup>Solutions Through Advanced Research, Jacksonville, FL

<sup>2</sup>UTHealth McGovern Medical School, Houston, TX

<sup>3</sup>Gold Skin Care Center, Nashville, TN

<sup>4</sup>Verrica Pharmaceuticals Inc., West Chester, PA

### ABSTRACT

**Objective:** Molluscum contagiosum (molluscum) is considered benign and self-limiting. However, the caregiver and patient experience largely remains a mystery. This online survey aimed to collect caregivers' views on their experiences with molluscum infection in their children, including diagnosis, treatment, and the impact of the virus on the caregivers' and their child's life.

**Methods:** Parents, caregivers, and/or legal guardians (ages 18+, 20% male and 80% female) of children diagnosed with molluscum in the past 4 years (ages 3-16 years of age) answered a 15-minute paid online survey with questions about their experience with molluscum.

**Results:** Caregivers (n=150) were mostly Caucasian (85%), 25-44 years of age (87%) and had at least one child with active molluscum (75%) at the time of the survey. The average number of health care providers (HCPs) consulted for molluscum was 1.95 and diagnosis was made by a variety of HCP types. The spread of molluscum to  $\geq 1$  child in the household was reported by 60% of caregivers in multi-child households. The average number of treatments used were 2.36 including HCP-administered treatments and consumer products. Caregivers reported moderate to major impact on their lives (62%) or their child's life (74%) due to molluscum.

**Limitations:** Questions were not validated, recall time was up to 4 years.

**Conclusions:** Molluscum patients may receive a diagnosis from many sources. Caregivers may utilize more than one treatment modality to help clear the infection including consumer products. Molluscum can cause an impact on quality of life for affected children and their caregivers.

### INTRODUCTION

Molluscum contagiosum (molluscum) is a common cutaneous viral infection that primarily affects children, the immunocompromised, and sexually active

adults. Molluscum is the third most common viral skin infection in children and one of the five most prevalent skin diseases worldwide.<sup>1</sup> The largest epidemiology study in children documented an average of 13.3 months to resolution without intervention; 30% of cases persisted at 1.5 years, and 13% at 2 years.<sup>2</sup>

July 2021 Volume 5 Issue 4

Molluscum may be associated with pain, itching, eczema, and secondary bacterial infections. Reasons for treatment of molluscum include alleviating discomfort, reducing risk of autoinoculation and spread to others, preventing scarring, and elimination of social stigma.<sup>3,4</sup> A survey of U.S. physicians found that the treatment of molluscum varies widely.<sup>5</sup> There are no FDA-approved treatments for molluscum, and non-approved treatments vary in safety and efficacy. The lack of treatment guidelines, safety concerns with current treatments, and the categorization of the infection as “benign” and “self-limiting”<sup>3,5</sup> may lead physicians to wait for natural clearance.<sup>3</sup> The choice of active non-intervention by physicians may be insufficient for caregivers, leading caregivers to take matters into their own hands. However, the habits of caregivers in attempting to treat the virus at home, including the use of consumer products or mechanical techniques (such as disturbing the lesions at home), have not been documented to date.

There are few studies reporting quality of life (QoL) concerns with molluscum and most are small or use generalized methods that may not highlight the unique concerns for molluscum patients and caregivers. In a study of parents of 30 children with molluscum, Braue et al.<sup>6</sup> reported molluscum moderately or greatly concerned 43% of children with the infection, along with 82% of their parents. Concerns were focused on physical issues such as scarring, itching, the chance of spread to peers, pain, and effects of treatment. In a larger study on QoL of a variety of skin diseases using the Children’s Dermatology Quality of Life Index (CDLQI)<sup>2</sup>, Olsen and colleagues reported an impact of 3.5 on a scale from 1-30 (n=5) for molluscum patients, which suggests a small impact of the disease. However, the questions on the

CDLQI may not be representative of the daily struggles that patients with molluscum or their caregivers face. For example, children with molluscum do not always experience itchy, sore, or painful skin with molluscum, may be able to hide the molluscum under clothing making it less obvious to friends/family, and there is no evidence that molluscum causes sleep loss or loss of school time. Thus, simply due to the type of questions asked on these measures, they may not be sensitive to the issues of the molluscum patient and may downplay the impact of the disease. Further measures are needed to elucidate the concerns of the caregiver and the patient. These questions do not shed light on the patient journey including diagnosis and treatment details.

This survey sought to uncover more information about the type and number of health care professionals (HCPs) seen for diagnosis, treatment patterns, and at-home remedy use, as well as the potential social stigma and impact of the disease on the patient and caregiver.

## METHODS

This voluntary survey was conducted using an online quantitative methodology from March 25th to April 2nd, 2020, among caregivers (parents and guardians) of children diagnosed with molluscum by a physician. Potential respondents were reached via a commercially available online panel sourced through Whitman Insight Strategies. Whitman Insight Strategies identified potential respondents and conducted the surveys. Individuals agreed to participate not knowing what potential surveys will be about. Respondents were pre-recruited through a variety of procedures including random-digit-dialing, email invitation from a partner website/ISP, or

client. In this survey, potential participants were emailed a link that directs them to a website where they were screened to determine if they qualified based on the outlined criteria and were then asked survey questions and paid for completing the survey. At survey initiation, the respondents gave written consent for their survey responses to be used and shared in future market research.

Respondents were required to be above 18 years of age and required to have at least one child who was diagnosed with molluscum by a physician in the past 4 years between 3 years and 16 years of age in the home. The survey targeted 80% female respondents and 20% male respondents to ensure appropriate representation of the gender of caregivers. Questions asked of the caregivers are listed in Table 1. Question topics included the types of HCPs that were consulted or had diagnosed the child with molluscum, incidence of spread of molluscum to another child in the home, the type of information shared with the caregiver by the doctor, impact on the caregivers' lives, impact on patients' lives, treatment modalities and at-home remedies, and demographics of the survey participants (Table 1). The margin of error at the 95% confidence interval for the total sample was  $\pm 7.7\%$ .

## RESULTS

### Demographics

The survey included 154 respondents who were caregivers of children diagnosed with molluscum. Most caregivers (75%, n=115/154) had children with an active infection, whereas 25% (n=39/154) had children with molluscum in the past 4 years but did not currently have an infection. Most respondents were Caucasian (85%,

n=131/154) with a median age of 36 (range 23-57), with a median home size of 4 (range 2-7), and with a median child age of 8 (range 1-16). Further demographic data can be found in Table 2.

### Diagnosis of Molluscum

Caregivers consulted many different types of HCPs about their child's molluscum, including Dermatologists (42% n=65/154), Emergency Room Physicians (27%, 41/154), Family Practice Physicians (40%, 62/154), Infectious Disease Specialists (29%, 45/154), and Pediatricians (56%, 76/154). The HCP type that diagnosed the condition included a Dermatologist (34%, 52/154), Emergency Room Physician (21%, 32/154), Family Practice Physician (37%, 57/154), Infectious Disease Specialist (23%, 36/154), and Pediatrician (49%, 76/154) (Table 3). The average number of physicians a caregiver consulted was 1.95 (Table 3). When asked if it was challenging to find a doctor who would tell caregivers about treatment options and be willing to treat their child, 51% (79/154) agreed, 19% (29/154) were neutral, and 30% (47/154) disagreed.

When being counseled about molluscum by an HCP after diagnosis, 49% (76/154) of caretakers reported the HCP told them molluscum was caused by a poxvirus, with 79% (122/154) being told that because of the infectious nature of the virus, there should be steps taken to avoid exposure to others. A total of 55% (84/154) of caregivers remember being told by a physician that molluscum could be upsetting for themselves and their affected children, and 50% (77/154) were told the molluscum would go away on its own.

**Table 1.** Questions Asked of Caregivers about Their Child's Molluscum

Question	Answers
<b>Which of the following health care practitioners did you consult after you noticed the bump(s)?*</b>	Dermatologist Emergency room physician Family practice physician Infectious disease specialist Pediatrician Other
<b>Which of the following health care practitioners told you your child has molluscum or diagnosed your child with molluscum?*</b>	Dermatologist Emergency room physician Family practice physician Infectious disease specialist Pediatrician Other
<b>You mentioned you have more than one child under the age of 16 in your household. Has molluscum ever spread from one child to the other within your household?</b>	Yes No Don't know
<b>Which of the following do you remember the doctor telling you?*</b>	Molluscum is caused by a poxvirus Since molluscum is contagious, we should take steps to avoid it Molluscum can be upsetting for caregivers and children There are treatments for molluscum that we can consider Molluscum will go away on its own None of the above
<b>How much of an impact has the molluscum had on your [affected] child's life?</b>	No impact Minor impact Moderate impact Major impact
<b>How much of an impact has the molluscum had on your [the caregiver's] life caring for your child with the infection?</b>	No impact Minor impact Moderate impact Major impact
<b>How much do you agree or disagree with the following statement?</b> <i>I worried about what other people thought about our family having a child with molluscum</i>	Strongly disagree Somewhat disagree Neutral Somewhat agree Strongly agree
<b>How much do you agree or disagree with the following statement?</b> <i>Molluscum kept my child away from doing the things they love</i>	Strongly disagree Somewhat disagree Neutral Somewhat agree Strongly agree
<b>How much do you agree or disagree with the following statement?</b> <i>It was challenging to find a doctor who would tell me about treatment options and be willing to treat my child</i>	Strongly disagree Somewhat disagree Neutral Somewhat agree Strongly agree
<b>Which of the following best reflects the doctor's recommendation when your child was first diagnosed with molluscum?</b>	The doctor recommended we let molluscum run its course and heal on its own The doctor told us about treatment options

**Which of the following ways of dealing with the molluscum did you decide on for your child\***

- Cryotherapy or cryosurgery (i.e. the doctor freezes off each bump with liquid nitrogen)
- Curettage (i.e. the doctor pierces the bump and scrapes off the skin with a small tool)
- Cantharidin or beetle juice (i.e. doctor applies a liquid that causes blistering)
- Home remedies
- Molluscum treatment from Amazon or drug store with no Rx required
- Squeezing and/or removing the bumps or material inside the bumps by myself
- Other (specify)

\*Questions where respondents were allowed to choose all answers that applied

Sixty percent (65/108) of caregivers with more than one child in the home reported spread of the infection from one child to another. A total of 76% (117/154) caregivers remember their doctor telling them there are treatment options to consider.

### Treatment Modalities

A large majority (76%, 117/154) of caregivers were told by an HCP that there were treatments to consider whereas 61% (94/154) had treatment options explained to them. A total of 39% (60/154) of caregivers reported that an HCP recommended they let the infection run its course. The average number of treatments utilized per caregiver response was 2.36. Twenty-seven percent (42/154) of caregivers reported that they considered removing the lesions themselves at home, and 20% (30/154) of caregivers strongly considered doing so. Many modalities were eventually used to treat the infection, including cryosurgery (41%, 63/154), curettage (31%, 47/154), compounded cantharidin (39%, 60/154), home remedies (43%, 66/154), molluscum therapies from a pharmacy or online store (44%, 68/154), and squeezing and/or removing the lesions or the core of the lesions at home (31%, 48/154), or other (7%, 11/154) (Figure 1). Under "Other", respondents included letting it run its course (n=7), prescription creams from a physician (n=2), not decided yet (n=1), and creams and bleach baths (n=1) (Figure 1).

### Impact of Molluscum on the Caregiver and Patient

In responding to the statement "Molluscum kept my child away from doing the things they love," 71% (109/154) of caregivers responded with agreement, 14% (22/154) were neutral, and 15% (24/154) disagreed. The majority of caregivers (62%, 95/154) worried about what people thought about their family having a child with molluscum (Figure 3). Caregivers also reported an impact on their lives caring for a child with molluscum, expressing mostly major (25%, 38/154) or moderate impact (38%, 58/154) (Figure 3). When asked about the impact on their children's lives, 26% (41/154) of caregivers responded with major impact, and 47% (73/154) responded with moderate impact (Figure 3).

## DISCUSSION

Previous smaller studies have shown that molluscum can impact caregivers and their children with molluscum. However, the level of impact and information on the journey of the caregivers and child in seeking resolution of the disease is limited due to smaller studies with less sensitive measures.<sup>2,6</sup>

This survey elucidates important information on the journey to diagnosis and treatment, as well as the impact on quality of life of the patient and their caregiver. Caregivers reported seeing multiple HCPs for a diagnosis and treatment, and some reported that it could be a challenge to find an HCP that was willing to treat their child. This could

**Table 2.** Survey Respondent Demographics and Characteristics

Respondents (N=154)	
<b>Household Information</b>	
<b>Median Number of people in the home – No. (range)</b>	4 (2-7)
<b>Household size – No. (%)</b>	
2-3 People	44 (28)
4-5 People	94 (61)
6+ People	16 (10)
<b>Mean age of children in the home in years – Yrs. (range)</b>	8 (1-16)
<b>Age of Children in the Home – No. (%)*</b>	
≤ 3 years	48 (31)
4-8 years	80 (52)
9-12 years	77 (50)
13-16 years	67 (43)
<b>Caregiver Gender – No. (%)</b>	
Male	31 (20)
Female	123 (80)
<b>Molluscum Status – No. (%)</b>	
Child currently has molluscum	115 (75)
Child had molluscum in the last 4 years	40 (25)
<b>Spread of molluscum from one child to another in the home**</b>	65 (60)
<b>Ethnicity – No. (%)</b>	
White/Caucasian	131 (85)
Black/African American	16 (10)
Asian	6 (4)
Native Hawaiian/Pacific Islander	1 (1)
American Indian/Alaskan Native	2 (1)
Other	3 (2)
<b>Homestead information – No. (%)</b>	
City	79 (51)
Suburb	65 (42)
Small town/rural	10 (7)

\*Caregivers could have more than one child in the home

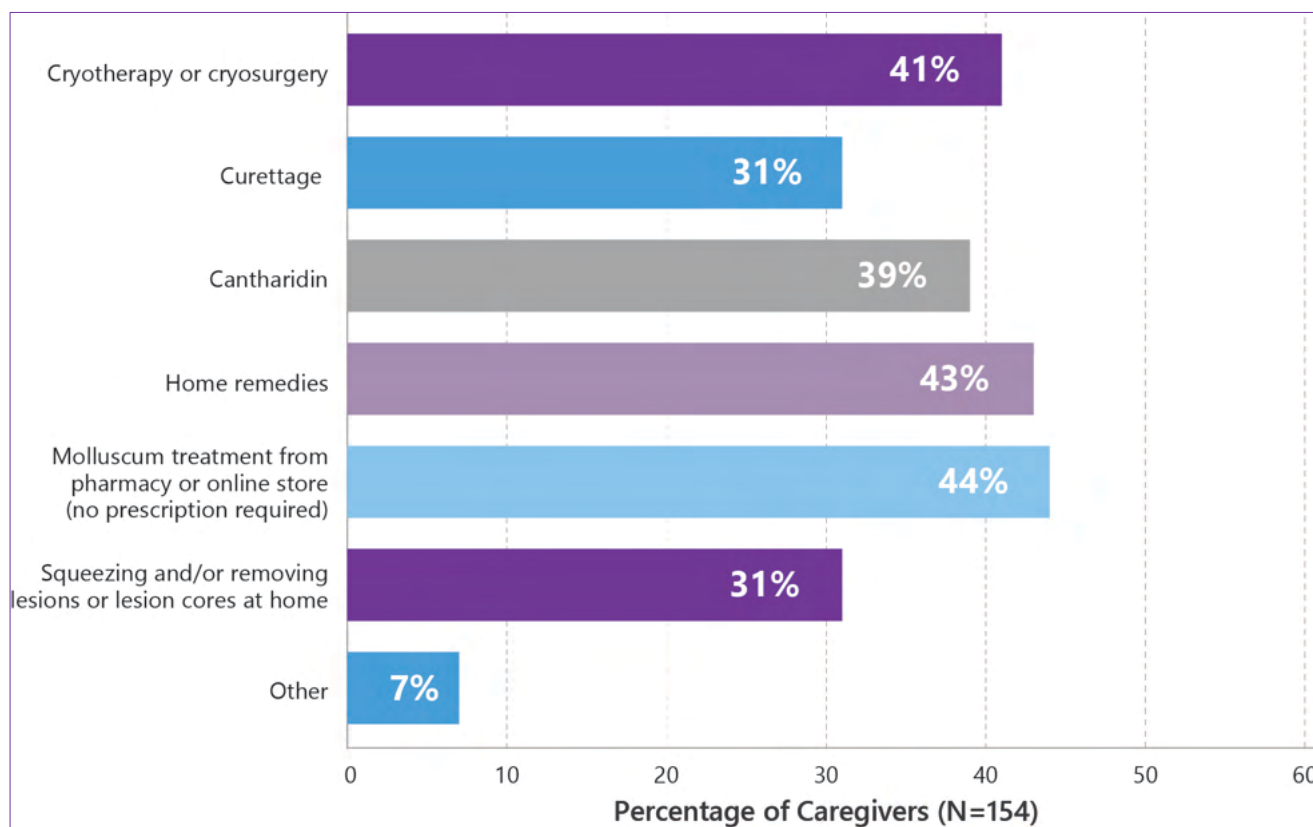
\*\*In homes of >1 child (n=108)

**Table 3.** Diagnosis and Treatment Responses

N=154		
<b>Average Number of Physicians Consulted Per Caregiver</b>	1.95	
<b>Type of HCP – No. (%)*</b>	<b>Consulted for Diagnosis</b>	<b>Diagnosed Molluscum</b>
Dermatologist	65 (42)	52 (34)
ER Physician	41 (27)	32 (21)
Family Practice Physician	62 (40)	57 (37)
Infectious Disease Specialist		
Pediatrician	87 (56)	76 (49)
<b>HCP Treatment Recommendations – No. (%)</b>		
Active Non-Intervention	60 (39)	
Offered Treatment Options	94 (61)	

suggest either lack of HCP knowledge on the molluscum diagnosis, a need for a referral to a specialist for identification or specialized treatment, or a choice by the HCP to allow the infection to run its course leading to “doctor shopping” by caregivers seeking treatment for their child.

Currently there are no FDA-approved treatments for molluscum, and treatments utilized may not be appropriate for young patients due to pain or side effects. In the absence of safe and effective treatment options, caregivers may be proactive to help their child get rid of the infection. Survey results showed that there was a discrepancy in the percentage of caregivers that were told there were treatment options (79%) vs. those that had the treatments described (61%), suggesting that some HCPs may have mentioned treatments were available, but that letting the disease run its course was the best course of action, or that caregivers chose not to use available treatments.



**Figure 1.** Responses to the Question: “Which of the following ways of dealing with molluscum did you decide on for your child?”\*

\*Caregivers may have utilized more than one treatment modality for their child

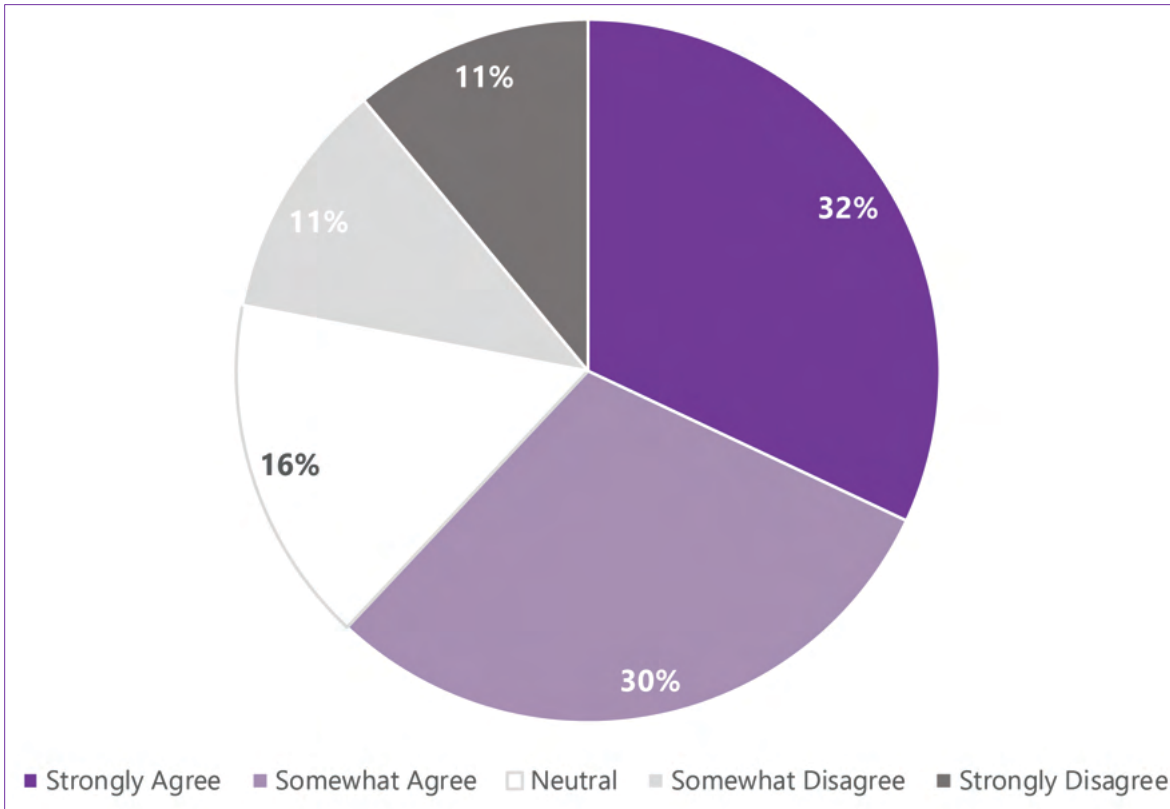
In those caregivers that opted for treatment, many different modalities were utilized including in-office, at-home, and consumer/home remedies, with an average of 2 treatments used by caregivers for their children with molluscum. The use of at-home remedies potentially represents a need by the caregiver to seek a solution if none is offered or if their current HCP-recommended treatments are not meeting expectations for safety, efficacy, or speed of resolution. Using unproven consumer or at-home remedies may result in a lack of efficacy, skin reactions, as well as a potential for spread of the disease to other areas of the body or other people.<sup>4</sup>

The number of caregivers that attempted to squeeze or remove the lesions at home is most concerning, given the contagious

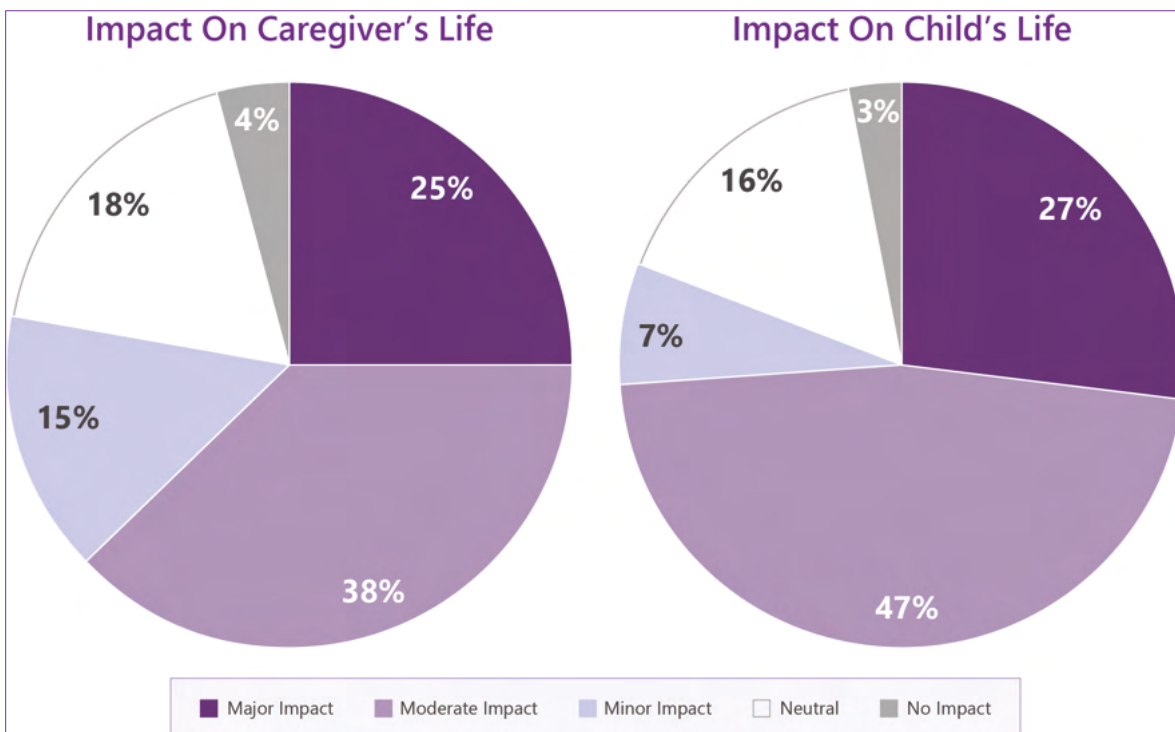
nature of the infection and the amount of virus found in lesion material.<sup>7</sup> Despite most caregivers in the study being warned about the infectious nature of the disease, many reported the spread of molluscum to other caregivers reported an impact of caring for a child with molluscum on their lives as well as their children’s lives, including a limitation of activities their child enjoys. The majority of caregivers expressed concern over social stigma, including worrying about what others thought of their family having a child with molluscum.

This research had several limitations. Survey respondents were paid and there were requirements on the percentage of genders of caregivers (to ensure accurate representation), the time since the child had molluscum (for recall purposes), as well as

July 2021 Volume 5 Issue 4



**Figure 2.** Responses to the statement "I worried about what people thought about our family having a child with molluscum"



**Figure 3.** The level of impact reported for molluscum on the caregiver's life (left) and on the child's life (right)



requirements of ages of children. The survey questions had not been tested for validity or reliability, and further research is warranted in this area. Levels of severity or impact of QoL questions were not defined, leaving the parameters up to interpretation by the respondent. In addition, diagnosis of molluscum was based on respondents' attestation, and only included caregivers' view of their and their children's experience with molluscum. These aspects could limit the generalizability of the conclusions.

## CONCLUSION

In conclusion, this survey shows that the journey to a diagnosis of molluscum may require seeing several types of HCPs, and many patients may not receive the option of treatment or may try more than one option. Caregivers may take matters into their own hands to treat their child's molluscum at home with unproven modalities or by disturbing lesions, which can cause safety concerns or the spread of the infection. There is a clear unmet need for education on diagnosis for HCPs and techniques on mitigating the spread of the infection for caregivers. Future research using validated measures is needed to further evaluate the impact of the disease and the patient journey toward diagnosis, treatment, and clearance for patients with molluscum and their caregivers.

**Acknowledgements:** We express great gratitude for Ms. Sheila Kennedy and her work in formulating the survey questions, and Dr. Christine Crosby for her editing assistance. Finally, we thank the respondents of the survey for sharing their experiences with us.

**Conflict of Interest Disclosures:** Dr.'s Kwong, Hebert, and Utlely have received consulting funds from advisory boards for Verrica Pharmaceuticals Inc. Dr. Kwong has received research funds for studies unrelated to this survey from Verrica

Pharmaceuticals Inc. Dr. Olivadoti is an employee of Verrica Pharmaceuticals Inc. and receives a salary.

**Funding:** Funding for the creation and management of the survey and data output was provided by Verrica Pharmaceuticals Inc. to Whitman Insight Strategies. Funding was also supplied by Verrica Pharmaceuticals Inc. to Versant Learning Solutions for creation of graphs.

**Corresponding Author:**

Melissa Olivadoti, PhD  
44 W Gay Street  
Suite 400  
West Chester, PA, 19380  
Email: [medinfo@verrica.com](mailto:medinfo@verrica.com)

**References:**

1. Shisler JL. Immune evasion strategies of molluscum contagiosum virus. *Adv Virus Res.* 2015;92:201-252.
2. Olsen JR, Gallacher J, Finlay AY et al. Time to resolution and effect on quality of life of molluscum contagiosum in children in the UK: a prospective community cohort study. *Lancet Infect Dis.* 2015;15(2):190-195.
3. Silverberg N. Pediatric molluscum contagiosum: optimal treatment strategies. *Paediatr Drugs.* 2003;5(8):505-512.
4. van der Wouden JC, Menke J, Gajadin S, et al. Interventions for cutaneous molluscum contagiosum. *Cochrane Database Syst Rev.* 2006(2):CD004767.
5. Hughes CM, Damon IK, Reynolds MG. Understanding U.S. healthcare providers' practices and experiences with molluscum contagiosum. *PLoS One.* 2013;8(10):e76948.
6. Braue A, Ross G, Varigos G, Kelly H. Epidemiology and impact of childhood molluscum contagiosum: a case series and critical review of the literature. *Pediatr Dermatol.* 2005;22(4):287-294.
7. Chen X, Anstey AV, Bugert JJ. Molluscum contagiosum virus infection. *Lancet Infect Dis.* 2013;13(10):877-888.