

This is a post-peer-review, pre-copyedit version of an article published in Journal of Autism and Developmental Disorders. The final authenticated version is available online

<http://doi.org/10.1007/s10803-020-04504-5>

Title

Skin picking in people with Prader-Willi syndrome: Phenomenology and management

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Abstract

Skin picking is highly prevalent in people with Prader-Willi syndrome (PWS). This study addressed the temporal (frequency, duration) and wider characteristics (e.g. type of skin picked, apparent motivations, or management strategies) of skin picking to inform intervention strategies. Nineteen parents/carers who observe skin picking shown by the person they care for completed a semi-structured interview. Results were consistent with previous research but advanced the field by finding that most participants picked skin with an imperfection and that parents/carers most commonly use distraction as a management strategy. Interventions that are behavioural, support emotion regulation and/ or are used in the typically developing population are therefore likely to be beneficial for future research.

Keywords

Prader-Willi syndrome, skin picking, self-injurious behaviour, neurodevelopmental disorder;

Acknowledgements

Thank you to all the families who took part. Thank you to Emma Shepherd for support with coding the interviews.

Funding

None

Conflict of interest

None

Author Note

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Thank you to the families who took part making this research possible. Thank you to Emma Shepherd for supporting the research by coding the interviews.

This paper was prepared for the first authors doctoral thesis for Doctorate in Clinical Psychology.

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Title

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Abstract

Skin picking is highly prevalent in people with Prader-Willi syndrome (PWS). This study addressed the temporal (frequency, duration) and wider characteristics (e.g. type of skin picked, apparent motivations, or management strategies) of skin picking to inform intervention strategies. Nineteen parents/carers who observe skin picking shown by the person they care for completed a semi-structured interview. Results were consistent with previous research but advanced the field by finding that most participants picked skin with an imperfection and that parents/carers most commonly use distraction as a management strategy. Interventions that are behavioural, support emotion regulation and/ or are used in the typically developing population are therefore likely to be beneficial for future research.

Keywords

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Prader-Willi syndrome (PWS) is a rare neurodevelopmental disorder caused by the loss of paternal information from chromosome 15, area q11.2 – 13. This information can be missing due to a paternal deletion, a maternal uniparental disomy (mUPD) or an imprinting error (Cassidy & Driscoll, 2009). It is associated with mild to moderate intellectual disability (Whittington et al., 2004) and a distinct behavioural phenotype that includes skin picking. The prevalence rates of skin picking in this population are high with most studies reporting estimates between 64-78% (removed for blind review) compared to 1-4% in the typically developing population (Odlaug & Grant, 2008; Roberts O'Connor and Bélanger, 2013). Skin picking has major short term and long term negative consequences, including wounds, scars, infections and detrimental effects on psychological wellbeing such as feelings of guilt (Didden et al., 2008; Hall, Hammond & Hustyi, 2013; Morgan et al., 2010; Van Ameringen, Patterson & Simpson, 2014; Grant et al., 2012; Roberts et al., 2013)

A recent systematic review highlighted key aspects of the phenomenology of skin picking in people with PWS that were not well described (removed for blind review) including the temporal characteristics and the type of skin picked. Furthermore, studies have reported varying functions (triggers) of the behaviour. The type of skin typically picked by individuals with PWS comprises both healthy and imperfect skin e.g. skin with a spot or scab (Morgan et al., 2010; Buono, et al., 2005). However, this has only been assessed by two studies, which did not address whether people were more likely to pick one type of skin than the other or whether people start picking more often at areas that are damaged compared to those that are not. Furthermore, only two studies (one, a case study) have considered the way that people with PWS pick at their skin, both reported that fingers or fingernails were used (Hall et al., 2013; Morgan et al., 2010).

When examining the temporal characteristics of picking, studies have reported wide ranging frequency and duration, with none clearly defining the categories used, for example

“frequent” (Hall et al., 2013; Morgan et al., 2010; Wigren & Heimann, 2010; Didden et al., 2008; Buono et al., 2005). In addition, only one study has assessed the duration of skin picking (Morgan et al., 2010).

The function of skin picking, an operant term referring to the maintenance of a behaviour through positive or negative reinforcement, has been examined but results are inconclusive. However, most studies have employed traditional behaviour functional assessment techniques, tailored to a few potential categories. Thus, authors have suggested that skin picking is positively reinforced by the sensory stimulation it produces or negatively reinforced by providing relief from high emotional arousal (Hall et al., 2013; Hustyi et al., 2013; Morgan et al., 2010; Didden et al., 2008; Didden et al., 2007). These conclusions have typically been drawn when behaviours appear to have no socially communicative function. However, the assessments used have limitations, such as retrospective report, reliance on informant report (Toogood & Timlin, 1996) and use of questionnaire measures limiting more specific exploration of PWS specific phenomenon, which make it difficult to draw clear inferences.

Various pharmacological interventions for skin picking have been evaluated with most reporting improvements (Miller & Angulo, 2014; Ye et al., 2013; Banga & Connor, 2012; Shapira et al., 2004; Benjamin & Buot-Smith, 1993). However, the majority of this research employed case series designs and often potentially confounding variables were not controlled for. Only one study used a double blind placebo controlled research design (Selikowitz et al., 1990). Two recent studies have started to explore behavioural interventions for skin picking in people with PWS (Wilson et al., 2012; Radstaake et al., 2011). The interventions employed evidenced success, but both studies are single case reports. Importantly, no studies have assessed any interventions that parents, carers or people with PWS themselves might use.

The limitations associated with the previous research on skin picking in terms of lack of clarity on the properties of the picking action, imprecision in reporting of the temporal characteristics, lack of conclusiveness on the function of (motivations for) skin picking, and lack of exploration of behavioural management strategies that may be employed by individuals with PWS or their families, mean that the route to development of potentially effective psychological and behavioural management strategies is currently unclear. Here, we aim to address these limitations with a view to informing the development of such management strategies. Thus, the present study aimed to gather more detailed information about the phenomenology of skin picking in people with PWS over and above information already available in the literature. Furthermore, there was a specific focus on factors that could feed into the development of effective treatment approaches

Method

Participants

Participants were included who had a diagnosis of PWS and who were currently engaging in skin picking. (removed for blind review) ethical review committee approved this research. Informed parental consent and child assent was ascertained for all participants under 16 years old, and informed consent from all participants aged 16 years and above.

See *Table 1* for participants demographic information. No formal measure of level of intellectual disability was included. However, for those participants who had taken part in a questionnaire study an indication of their level of ability could be provided by informant report answers on the Wessex Scale (Kushlick et al., 1973) which assess motor skills, verbal abilities and daily living skills. The scale categorises as not mobile, partly mobile or fully mobile. For verbal abilities it classifies participants as verbal or non-verbal and considers

someone verbal if they can say a few words. Information from the scale was unavailable for four participants.

[Table 1]

Measures

Semi-structured interviews have been used to examine aspects of the behavioural phenotype of PWS (Tunnicliffe et al., 2014; Woodcock et al., 2009). These studies have demonstrated the utility of such interviews for developing a fine-grain understanding of a behaviour profile, which can be applied for intervention development (Robb, Waller & Woodcock, 2019). For this reason, a semi-structured interview schedule was developed for the present study. The schedule included open and fixed choice questions. The design was based on a previous semi-structured interview for assessing temper outbursts in people with PWS (Tunnicliffe et al., 2014). This interview had good inter-rater reliability and showed convergent validity with another measure of temper outbursts, a behaviour diary (Bull et al., 2015). Open questions were designed to allow free response from informants whilst minimising bias from the interviewer. Written prompts were included for these questions if informants were finding questions difficult to answer. Fixed choice questions included those questions asking for a “yes”, “no” or “don’t know” response. Additional fixed choice questions were used for assessing the frequency and duration of skin picking. The fixed choice question and answers were taken from the Challenging Behaviour Interview (CBI; Oliver et al., 2003), with permission from the author, which addressed the frequency and duration of challenging behaviour. These items in the CBI (Oliver et al., 2003) had good inter-rater reliability (.69) and test retest reliability (Pearson’s $r = .90$).

Content of the questions was based on previous research and was in line with the objectives of the study. The question content included the frequency and duration of skin picking, the

age at which skin picking first began, body sites targeted, the type of skin picked, method used to pick and damage to the skin. Informants were also asked about precursor behaviours to skin picking (behaviours that occur directly before a target behaviour; Najdowski et al., 2008), emotion during and after skin picking and what happens after skin picking (e.g. whether participant seeks help or talks about it). Antecedents to skin picking were ascertained by asking informants to think about the last time the participant showed skin picking, (similar to Tunnicliffe et al., 2014). Informants were also asked about any intervention strategies that they or the person with PWS use, both preventative and reactive, and how successful those interventions were. Additional questions were constructed based on findings of previous research such as the desire of the person with PWS to stop skin picking, ability of the person to stop skin picking, what a person with PWS might say about their skin picking and if the person shows any signs of pain whilst skin picking. *Table 2* outlines the questions including identifying those that were open or fixed choice. The full interview schedule is provided in the supplementary materials.

[Table 2]

Procedure

Participants were recruited from an international conference for PWS that was based in the UK in July 2013 (n=4) and from an already established database of families affected by PWS (n=15). The existing database included 61 families eligible to be contacted. Those families had indicated that they would like to be contacted about future research, and, as of July 2011 to February 2012, included a person with PWS whose caregivers reported they were engaging in skin picking. Of these 61 families, 25 (41%) were uncontactable, one (2%) was deceased, five (8%) were no longer currently engaging in skin picking, three (5%) were not able to provide their informed consent due to their level of intellectual disability, three (5%) were not

interested, one (2%) was unable to take part due to a stressful life event and eight (13%) did not return a signed consent form.

After written informed consent had been provided, informants were contacted at an arranged time to conduct interviews which lasted between 15 minutes and 56 minutes with a mean duration of 25.5 minutes. All interviews were conducted by the first author.

Coding

A coding scheme quantified responses to minimise researcher bias and ensure comparability across participants. The coding template was created once all interviews had been conducted which is the process recommended to ensure representativeness and minimise any amendments to the coding scheme that may need to be made and therefore minimises errors in coding (Oppenheim, 2005). See *Table 2* for the coding instructions used.

Inter-rater reliability

A second researcher independently coded eight (42%) of the interviews using the coding scheme. The percentage agreement at an item by item level for each overall interview was calculated. *Table 2* shows the item level agreement; the mean item level agreement was 88.01% (range 62.5% to 100%).

Results

Phenomenology of skin picking

Table 3 shows the data collected on the phenomenological aspects of skin picking identified. The most commonly reported age at which skin picking began was between 3 and 8 years old, with one as young as 18 months and the oldest 13 years old. The majority of informants reported the legs, hand, arms and face as the most common sites of injury.

[Table 3]

The majority of informants reported that the type of skin picked most commonly was that with an imperfection. Examples of imperfections included sore skin, dry skin, cut/scratch/graze, spot, insect bites, sunburn, eczema, itchy skin and scarring. Eight informants reported that both healthy and imperfect skin were picked. One informant said that anxiety influenced the type of skin picked with healthy skin being picked when feeling particularly anxious. Only one informant reported healthy skin to be the only type of skin picked. All participants used their fingers or fingernails to pick their skin with. An additional six informants reported that the person they care for used their teeth as well to bite at the skin. Two informants reported that in the past, the person they cared for used objects to pick with (scissors and a safety pin).

A wide range of frequencies was evident. Nine informants reported that skin picking was not regular in frequency but seemed to occur more sporadically, the majority of informants attributed increases in frequency to periods of higher anxiety. However, eight informants said that skin picking frequency did not change and was fairly constant over time.

The majority of informants reported that the duration of each episode of skin picking had typically lasted less than an hour but more than 15 minutes. When asked about the longest episode in the last month, all but three informants reported that no episode had exceeded the typical duration. For one participant skin picking was reported to last for over an hour because the participant was not interrupted from doing it. This informant reported that they

thought that the person they care for would continue to pick unless interrupted or stopped by someone else.

All but one informant reported that skin damage due to skin picking had occurred in the past year. Of those who reported damage, all reported multiple types of skin damage and that bleeding had occurred.

Antecedents, Precursors and Events Subsequent

Informants reported a variety of different antecedents and some reported multiple antecedents. The most common were anxiety (n=9), a skin imperfection combined with unoccupied hands (n=6) or boredom (n=5), boredom and hands not being occupied (n=4). Other triggers reported by two informants were feeling hungry and tired. The remaining triggers were identified by only one informant each (feeling hot, angry or unwell, being alone or inactive, being told “no”, a skin imperfection and because the person wants to do it).

Informants found it difficult to differentiate between an antecedent and a precursor behaviour. Therefore, data from informants who reported the same antecedents and precursors were not included. Five informants did not identify any precursors and one was unsure. Two informants identified that rubbing skin/scab was a precursor. Finally one informant reported that difficulty concentrating was a precursor and one reported that being quiet was a precursor.

After skin picking, the majority of participants (n=11) were reported to try to hide the results their skin picking. Six participants requested a plaster/bandage or help whereas five participants were reported to not talk about it, and two to deny having done it. Other participants (n=3) apologised for picking or say negative statements about having done it, for example “I was silly”, “I shouldn’t have done it”. Five participants engaged in conversations

about their skin picking wounds and how they are healing. Finally, two participants were reported to often say “I can’t help it” after having picked.

Emotions associated with skin picking

Informants described the emotion that the person can show during and after skin picking, see *Table 4*. The most common emotions reported in either situation was feeling relaxed/content/happy. Anger and guilt were emotions only reported to occur after skin picking, anger seemed to occur if a person was interrupted or reprimanded about picking. One informant identified that the person that they care for would usually feel anxious when they start a new wound but normally happy and content when picking an already established skin picking wound. Additionally, five informants commented that during skin picking the person they care for appears to be extremely focussed upon what they are doing.

[Table 4]

Time spent looking at skin

Most participants (n=10) were reported to spend 100% of the time looking at the skin and one participant between 80-90% of the time. On the other hand, three participants were reported to not look at their skin, two participants were reported to look around 10% of the time and one participant around 20-30%. Two informants were unsure.

Pain

All informants said that that the person they care for showed no signs of pain whilst skin picking except for two informants who said that they were not sure as skin picking was done in private.

Ability to stop and desire to engage in skin picking

The majority of informants said that the person they care for can stop picking when asked to. Most informants reported that each time a person engaged in skin picking they wanted to do it. However, two informants reported that they thought the person they care for engaged in skin picking without thinking or being consciously aware. One informant thought that the person could not help doing it and two informants thought that sometimes the person they care for engaged in skin picking even though they did not want to.

Management strategies

Table 5 highlights the management strategies used by informants, some were preventative to avoid it happening and others were reactive (used once a skin picking episode had begun). The most common preventative strategy reported by informants was distraction (shifting a person's attention or focus onto something else either by giving a task or engaging in conversation). However, other preventative strategies were more practical such as keeping nails short and skin moisturised. Of those who reported using a preventative strategy, nobody reported preventative interventions to be successful all of the time.

[Table 5]

Informants reported multiple reactive strategies, but the most common one was distraction.

Informants reported reasons why they would use different reactive strategies, the most

common being whether the person was actively engaging in skin picking or not. Other reasons were the severity of skin picking or damage, if the principal intervention did not work, being in a public place, the person's mood and the availability of the informant to implement a strategy. Four informants reported that they did not use reactive strategies either because they were not successful or because the person was an adult so it was difficult to use reactive strategies.

The majority of informants said the person with PWS did not have their own management strategy. Four participants used their own strategies such as, flicking fingers together, and self-talk such as "don't pick" but only one participant consistently used the strategy.

Discussion

This is the first study to explore the phenomenology of skin picking in a large number of individuals with PWS in detail, alongside strategies used by individuals and families to reduce to skin picking. Participants were found to mostly pick skin with an imperfection using their nails and the frequency of skin picking varied. Triggers most commonly reported were anxiety or boredom, however, the majority of participants were identified as appearing relaxed, happy or content during and after picking. Informants reported using both preventative and reactive strategies which most commonly was distraction techniques. People with PWS mostly did not appear to have their own strategy to manage skin picking.

In line with previous literature, age of skin picking onset here was between three and eight years old (Wigren & Heimann, 2010; Buono et al., 2010; Didden et al., 2007; Buono et al., 2005); most common picking sites were legs, hand, arms and face and participants appeared to pick multiple sites (Husty et al., 2013; Buono et al., 2010; Morgan et al., 2010; Didden et

al., 2008; Didden et al., 2007); and all participants picked using their fingers or fingernails (Hall et al., 2013; Morgan et al., 2010).

However, although previous research has indicated that both healthy skin and skin with imperfections can be picked (Morgan et al., 2010; Buono et al., 2005), here we showed that imperfect skin was most commonly picked. Since skin picking typically onsets in early childhood, this finding suggests that early intervention aiming to prevent skin picking from developing may be beneficial. Monitoring skin in key injury sites and trying to keep skin as imperfection free as possible (e.g. moisturising skin) may be beneficial. Families with children with PWS are already advised around early intervention with food related issues (McAllister et al., 2011) so the PWS community may be in a good position to benefit from such early approaches.

Frequency of skin picking varied across participants as has been found previously (Wigren & Heimann, 2010; Buono et al., 2005). However, here we showed that skin picking most commonly occurred on a weekly or monthly basis. This operationalisation of frequency in terms of real time should be considered in future intervention evaluations research. If skin picking is shown weekly or monthly then observational measures of skin picking are likely to be inappropriate, except if administered by caregivers who are with participants for extended periods.

Most of the present participants tended to skin pick for more than fifteen minutes but less than an hour. This is in contrast to the one study that found skin picking episodes to most commonly last for less than five minutes (Morgan et al., 2010). However, Morgan et al., (2010) used a questionnaire with different response options, which may have influenced responding. The present finding suggests that at least some individuals with PWS skin pick in extended episodes. It seems likely therefore, that given the weekly/monthly frequency, most

damage inflicted by picking occurs during the escalation of individual episodes. Thus an intervention strategy which limits the duration of skin picking episodes (rather than necessarily having to avoid them all together) may be effective in greatly limiting the damage associated with picking.

No participants showed any signs of pain whilst engaging in skin picking and no informant reported that the person they care for reported feeling pain, which is consistent with the high pain threshold associated with PWS (Cassidy et al., 1997). One possibility is that pain was being experienced, but there were no observable signs of pain, and future self-report work should seek to examine this possibility. However, if people with PWS are not receiving feedback in the form of pain when skin is damaged by picking, there is no immediately aversive cost, which may play a role in the demonstration of the skin picking (Oliver & Richards, 2015). Pain functions to direct attention towards the painful stimuli and motivates a person to escape from the pain (Eccleston & Crombez, 1999). Without a pain signal, skin picking may continue for long periods of time (which is consistent with the presently reported long durations of skin picking).

The majority of participants tended to look at the skin they were picking. This finding is supported by Morgan et al. (2010) who found that more severe skin picking was associated with “focussed” picking (that the person is paying attention to). The authors of this paper argued that this demonstrated that skin picking was a compulsive behaviour and that it is not done automatically. Research into skin picking in the typically developing population conceptualises it as a compulsive behaviour due to the high comorbidity with obsessive compulsive disorder, the reported experience of urges to pick, and the fact that picking is engaged in with conscious awareness (Van Ameringen et al., 2014; Grant et al., 2010). Recent changes to DSM-5 (American Psychological Association, 2013) now incorporate skin picking under a broader category of “obsessive-compulsive and related symptoms”. Thus, it

is possible that in people with PWS there is an association between skin picking and other behaviours shown commonly in individuals with the syndrome that are described as “compulsive-like”. Links between skin picking and compulsive behaviours have been demonstrated by Didden et al. (2007) who found that skin picking and compulsive behaviours were positively correlated in people with PWS and that age of onset of skin picking and compulsivity also correlated. To understand the extent to which skin picking and other behaviours are truly compulsive, assessment of individuals’ urges to engage with the behaviours is necessary. Since such urges represent a personal thought process, valid self-report methodology would be required for such an assessment.

There were two main antecedents to skin picking identified here; feeling anxious and being bored with unoccupied hands. This supports the suggestions made in previous studies that skin picking for people with PWS may be negatively reinforced by reduction of high emotional arousal or positively reinforced by provision of sensory stimulation at times of little activity or boredom (Hall et al., 2013; Hustyi et al., 2013; Didden et al., 2007). Such settings for skin picking have also been identified in the typically developing population (Odlaug & Grant, 2012). In individuals with PWS specifically, there is growing evidence pointing towards wide reaching emotion regulation difficulties. For example, temper outbursts are extremely common in people with PWS and are associated with signs of heightened emotional arousal (Holland et al., 2003; Tunnicliffe et al., 2014). Some of the present informants reported using preventative strategies focused on trying to reduce anxiety, offering further support for the idea that interventions targeting difficulties in emotion regulation may be beneficial. Thus, it is possible that addressing the broader apparent difficulties in emotion regulation in individuals with PWS would have a beneficial effect on skin picking behaviour. Various pharmacological, medical and psychological approaches which may address such difficulties in emotion regulation in individuals with PWS are

currently under examination, including the use of mindfulness (Singh et al., 2017). Thus, in future research inclusion of potential changes in skin picking linked to these interventions may be beneficial. Other intervention approaches that aim to teach emotion regulation skills such as relaxation techniques often used in Cognitive-Behavioural Therapy (CBT; Beck, 1967) have not commonly been employed in individuals with PWS but further research on these may be beneficial.

Informants reported using more reactive strategies for times when somebody had already begun skin picking. The most common strategy reported was using distraction by engaging the person in an activity or more specifically giving them something to do with their hands. The use of distraction corresponds to behavioural techniques or differential reinforcement of incompatible behaviour or alternative behaviour that has been explored in two single case experimental designs (Wilson et al., 2012; Radstaake et al., 2011) and evidenced some efficacy. This suggests that such differential reinforcement approaches may be a feasible approach to caregiver led intervention. Thus, exploration of the wider utility of such differential reinforcement approaches in a manner that can be led by parents will be a very important avenue for future research. Since the differential reinforcement of incompatible behaviour approaches that have been examined specifically target the potential positively reinforcing nature of the sensory stimulation provided by the picking, these approaches may be particularly useful for those episodes of skin picking that appear to be triggered by periods of inactivity or boredom. Work in this area should be conducted in a manner that is sensitive to the possibility that such differential reinforcement would only address some instances of the behaviour. Furthermore, CBT, Habit Reversal Therapy and ACT (Gelinias & Gagnon, 2013) have been reported to be effective at reducing skin picking in those without an intellectual disability. It is possible that these interventions may be useful for people with

PWS particularly if the interventions are tailored to the needs of people with an intellectual disability.

Five participants were reported to have their own strategy to try to reduce their skin picking with only one consistently using the strategy. Furthermore, informants reported that the majority of participants appeared to be happy, content or relaxed whilst skin picking and after skin picking. This suggests that there are some people with PWS who engage in skin picking, who appear not to be distressed by skin picking and therefore, are perhaps not motivated to stop. This raises an important ethical question of whether intervening is appropriate if somebody does not want to stop skin picking. It would be important to consider on a case by case basis a person's understanding of their skin picking but also to assess any negative consequences to skin picking, particularly with regard to health and the damage that their skin picking may be causing. Furthermore, if a person does not have motivation to change then any intervention will be susceptible to failure (Prochaska, & DiClemente, 1982). Motivational interviewing for some people may be an important first step as this is a way of exploring a person's motivation to change and can help elicit change (Rollnick & Miller, 1995). Further research may benefit from asking people with PWS directly about their understanding of skin picking and the impact that it has. Only one study has explored this to date finding that participants did hold negative views of their skin picking behaviour (Didden et al., 2008).

One limitation of this research is that the interview was only able to explore skin picking that was observed by informants. Informants in this interview reported that sometimes people try to hide their skin picking or skin picking is only done when alone, therefore, this method of exploring skin picking is limited to only skin picking observable to informants. This area of research may be further enhanced by self-report interviews. A further limitation is that some of the questions asked informants to recall past events. This retrospective approach can be a

potential source of error in measurement as informants recall may be affected by forgetting or biases. It would be interesting to explore skin picking longitudinally to avoid this limitation. Another approach would be to ask participants to record skin picking on a daily basis to establish a more natural recording of skin picking without the threat to validity of relying upon informants' recall. Furthermore, the presently developed semi-structured interview had good inter-rater reliability, but its wider validity was not established, this would be a useful further direction to support further assessment of skin picking in the future. Interviews can also be subject to interviewer bias or influence, however, this was minimised by using a clear interview schedule with some structured prompts and by using a coding scheme in order to analyse the data.

Although a higher severity of skin picking has sometimes been reported in people with the deletion subtype of PWS (Hartley et al., 2005; Dykens et al., 1999; Symons et al., 1999), the present study could not examine differences across genetic sub-types due to the small numbers per group and lack of confirmation of genetic diagnosis. The research was therefore limited in this respect. Furthermore, we did not include a formal measure of intellectual ability. It would have been interesting to explore changes with age as some research has documented higher skin picking in adolescence (Dykens et al., 1992; removed for blind review) but lowest rates during adulthood (Akefeldt & Gillberg, 1999; removed for blind review). During the interviews at least three informants reported changes with age in skin picking, although this was not directly investigated.

Conclusion

This interview study has added to the research literature by further describing the phenomenology of skin picking. It has highlighted that skin with an imperfection appears to

be the most commonly type of skin picked and that there are no observable signs that pain is experienced whilst picking. Participants in this sample tended to look at the skin they were picking throughout suggesting that it may be useful to further explore whether this is a compulsive behaviour. Furthermore, this research has explored the types of management strategies that families or people with PWS use to try to manage skin picking and most commonly distraction techniques were reported as both preventative and reactive strategies. Future research may benefit from gathering self-report information, exploring potential emotion regulation difficulties in people with PWS but also interventions for skin picking in people with PWS. It may be helpful to draw on the more well developed psychological interventions used in the typically developing population to support this.

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Tables

Table 1: Participant demographic information

	Participants with Wessex Scale information	Total
N	15	19
Age range (years:months)	7:2 – 40:10	7:2 – 40:10
Mean age (standard deviation)	19:0 (10:1)	21:6 (10:4)
Gender (Male:Female)	5:10	8:11
Verbal ability (Verbal:Non-Verbal)	15:0	-
Motor skills (Mobile:Partly Mobile)	12:3	-
Daily living skills rated 3-9 range	5-9	-
Daily living skills rated 3-9 Mean (standard deviation)	7.30 (1.28)	-

Table 2: Interview questions, coding scheme and item level inter-rater agreement

Item details	Coding instructions	Inter-rater agreement (%)
How old was X when you first noticed skin picking?	Report age stated or “don’t know”	100.00
Where on their body is X most likely to skin pick?	Report body sites identified ensuring most common identified. If unable to identify state “don’t know”. Group according to body area as well.	93.75
Are there any other areas where X has skin picked?	Report all body sites mentioned	83.33
What type of skin does X skin pick?	Report all types identified or state “don’t know”	94.12
What type of skin was it before the picking began?	Report type or state “don’t know”	94.12
What type of skin does X now pick?	Report type or state “don’t know”	70.00
What is the method that X uses to skin pick?	Report the method that participants use or state “don’t know”	91.67
In the last year, has X damaged their skin when skin picking?	Report yes, no or don’t know	87.50
If yes....what damage?	Record type of damage caused	85.71
Think about how often skin picking has happened in the last month. If there was no change and you watched this person now, then would you <i>definitely</i> see more skin picking:	Fixed choice options taken from CBI (Oliver et al., 2003)	87.50
In the last month, for how long did the <i>longest</i> period of skin picking last for?	Fixed choice options taken from CBI (Oliver et al., 2003)	87.50
In the last month, how long have the periods of skin picking <i>typically</i> lasted on average?	Fixed choice options taken from CBI (Oliver et al., 2003)	75.00
Thinking about the longest period of skin picking in the last month that continued for over an hour- how long did it last?	Report duration if applicable or state “don’t know” if unable to identify	87.50
What keeps skin picking going for long periods of time?	Report reason given if applicable or state “don’t know” if unable to identify	77.78
Over a period of around 6 months, are there times when X seems to skin pick a lot followed by times when X does not skin pick at all?	State yes, no or don’t know. If yes documents reason for pattern	83.33
Are there any indicators before X starts to skin pick?	State yes, no or don’t know	66.67
Do these always happen?	State yes, no or don’t know. If no and frequency given state it or if none given report it	85.71
When you see these behaviours is there anything that you could do to prevent skin picking from occurring?	State yes or no. If yes document intervention	72.72
How likely is it to be successful? (out of 10)	Document success out of 10 or state if question not applicable	87.50
During a period of skin picking, how would you describe X’s emotion?	Report all emotions identified or report “don’t know”	89.47
What does X do after skin picking?	Report any behaviours, speech, emotions reported	91.67
How would you describe X’s emotion after skin picking?	Report all emotions identified or report “don’t know”	92.86

Are there any strategies that you have that can help stop X skin picking?	Report principal intervention or more than one if informant states so	88.24
Roughly how many times would you respond in this way?	Fixed choice answer as on interview schedule	62.50
In what other ways might you respond?	Report all other interventions used or state if there are no additional interventions	100.00
What are the reasons that you might respond in different ways?	Report reasons for using different interventions or state "don't know" of informant unable to identify	88.89
Are there any strategies that X has to help them to stop skin picking?	Report what identified	90.00
Roughly how many times would X do this?	Fixed choice answer as on interview schedule	87.50
Have you tried covering the area of skin that they are picking?	State yes or no	100.00
Was it successful?	State yes or no and any reasons given if applicable	90.00
When the area of skin was covered, did X start to pick anywhere else?	State yes or no if applicable	100.00
If you ask X to stop do they stop?	State yes, no or don't know	87.50
Do you think that they are able to stop?	State yes, no or don't know	100.00
Thinking about the last period of skin picking that X showed, what seemed to trigger it?	Listen to the description of the last episode and document the antecedent or state "don't know"	88.89
Would you say that this is the most common trigger? If not, what is?	Document the most common trigger	100.00
Out of 10, what proportion of all skin picking that X shows seem to be caused by the trigger that you have identified?	Document number out of 10 or state unable to answer	100.00
Does the trigger that you mentioned always result in skin picking? <i>If no</i> , out of 10, how often does the trigger that you mentioned result in a period of skin picking?	State yes, no or don't know. If no state frequency with number out of 10	77.78
What happens on the occasions that it does not trigger skin picking? What is different about these times?	Identify any reasons given or state if informant is unable to provide any	90.91
Are there other triggers?	Document all other antecedents or state if all have already been reported in above items	81.82
What percentage of the time does X look at what they are picking?	Report percentage given or state "don't know"	80.00
When X is skin-picking do they show any signs of pain?	State yes, no or don't know	100.00
Are there times when X skin picks even when you think that they don't want to do it?	State yes, no or don't know	100.00
What does X say about their skin picking?	State yes or no. If yes state what participant says or topic spoken about	87.50
Does X try to hide their skin-picking?	State yes or no	85.71

Table 3: Frequency table of the phenomenology of skin picking, form, frequency, duration and injury (n = 19)

Age of onset	0-2 years	3-5 years	6-8 years	9-11 years	12-14 years	Don't know		
	1	7	6	0	1	4		
Sites of injury*	Arms	Hands	Legs	Face	Torso	Site of any skin imperfection	Feet	Neck
Most common site	9	9	6	5	3	1	0	0
Other sites	3	4	3	4	3	7	4	1
Type of skin picked*	Skin imperfection	Healthy skin						
	18	9						
Method used to pick*	Fingers / fingernails	Teeth	Objects					
	19	6	2					
Frequency	In the next 15 minutes	In the next hour	By this time tomorrow	By this time next week	By this time next month	Don't know		
	1	3	3	4	6	2		
Duration	Less than a minute	Less than 5 minutes	Less than 15 minutes	Less than an hour	More than an hour	Don't know		
Longest duration	0	1	4	6	1	7		
Typical duration	0	2	4	6	0	7		
Damage to skin*	Sore red skin	Bleeding	Shallow wounds	Deep wound	Infection	Scarring		
	8	18	8	7	7	7		

*Participants could provide multiple responses to answer these questions

*Table 4: Emotion reported whilst skin picking and after picking and number of participants reporting each emotion (n = 19)**

Emotion	Whilst skin picking	After skin picking
Relaxed/content/happy	10	9
Anxious/tense	4	3
Bored	2	0
Sad/upset	3	5
Emotionless	1	0
Angry	0	3
Guilty	0	2

*Participants could answer these questions with multiple responses

Table 5: Frequency of preventative, reactive and self-management strategies reported (n = 19)

Prevention strategies*	Distraction	Reduce anxiety by talking	Keep skin moisturised	Keep nails short	Teach consequences	Draw attention to rubbing of skin	Plasters	Active schedule	No strategy reported			
	9	2	2	1	1	1	2	1	6			
Reactive strategies*	Distraction	Reprimand/ask to stop	Reward chart for not picking	Cover with plasters and distraction	Teach consequences	Cover with plasters	Hold hands	Put hand on arm	Act horrified	Discuss skin picking	Draw attention to it	No strategy
Main reactive strategy	6	1	3	1	2	0	1	0	0	0	1	4
Additional reactive strategy	2	2	1	0	0	4	1	1	2	2	0	8
Self-management strategy	Keeping busy	Flicking fingers together	Self-talk	No strategy	Not sure							
	2	1	1	14	1							

*Participants could answer these questions with multiple responses

Supporting Information

Interview Schedule

The aim of this interview is for us to get a better understanding of X's behaviour. In particular, we are interested in skin picking and how often it happens. We are also interested in how long it can last for and when it is more likely to happen. I'm going to ask you a series of questions that should take no longer than 30 minutes. Do you have any questions before we begin?

Name: _____ Gender: Male Female

Age: _____ Genetic subtype: _____

Name of respondent: _____ Date of interview: _____

1) How old was X when you first noticed skin picking?

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2) Where on their body is X most likely to skin pick?

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Are there any other areas where X has skin picked?

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3) What type of skin does X skin pick? (i.e. healthy, spot, scab, rash)

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What type of skin was it before the picking began?

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.....

What type of skin does X now pick?

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.....
.....

4) What is the method that X uses to skin pick? (i.e with fingernails, using an object)

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5) In the last year, has X damaged their skin when skin picking?

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.....

If yes....what damage? i.e. sore red skin, bleeding, deep wounds, scarring, infection, disfigurement

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.....

6) Think about how often skin picking has happened in the last month. If there was no change and you watched this person now, then would you definitely see more skin picking :

- | | | | | |
|------------------------|------------------|-----------------------|------------------------|-------------------------|
| In the next 15 minutes | In the next hour | By this time tomorrow | By this time next week | By this time next month |
|------------------------|------------------|-----------------------|------------------------|-------------------------|

7) In the last month, for how long did the longest period of skin picking last for?

- | | | | | |
|--------------------|---------------------|----------------------|-------------------|-------------------|
| Less than a minute | Less than 5 minutes | Less than 15 minutes | Less than an hour | More than an hour |
|--------------------|---------------------|----------------------|-------------------|-------------------|

8) In the last month, how long have the periods of skin picking typically lasted on average?

- | | | | | |
|--------------------|---------------------|----------------------|-------------------|-------------------|
| Less than a minute | Less than 5 minutes | Less than 15 minutes | Less than an hour | More than an hour |
|--------------------|---------------------|----------------------|-------------------|-------------------|

9) Thinking about the longest period of skin picking in the last month that continued for over an hour- how long did it last?

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10) What keeps skin picking going for long periods of time (i.e. for more than one hour)?

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11) Over a period of around 6 months, are there times when X seems to skin pick a lot followed by times when X does not skin pick at all?

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Prompt = Are there any patterns to X's skin-picking that you have noticed?

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12) Are there any indicators before X starts to skin pick?

Prompt = any indicators in X's behaviour?

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Do these always happen?

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13) When you see these behaviours is there anything that you could do to prevent skin picking from occurring?

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.....

How likely is it to be successful? (out of 10)

.....
.....

14) During a period of skin picking, how would you describe X's emotion?

Prompt= how do you think that X feels when X is skin picking?

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15) What does X do after skin picking?

Prompt= Do they do anything? Say anything?

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.....

16) How would you describe X's emotion after skin picking?

Prompt= how do you think X is feeling?

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17) Are there any strategies that you have that can help stop X skin picking?

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.....
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18) Roughly how many times would you respond in this way?

Always More often than not Sometimes
Occasionally Rarely

19) In what other ways might you respond? When would you respond in these ways?

Prompt: e.g. are there any differences at home compared to in public?

1.....
2.....
3.....
4.....
5.....

20) What are the reasons that you might respond in different ways?

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21) Are there any strategies that X has to help them to stop skin picking?

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22) Roughly how many times would X do this?

Always More often than not Sometimes
Occasionally Rarely

23) If not already mentioned.....

Have you tried covering the area of skin that they are picking?

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Was it successful?

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When the area of skin was covered, did X start to pick anywhere else?

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24) If you ask X to stop do they stop?

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Do you think that they are able to stop?

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25) Thinking about the last period of skin picking that X showed, what seemed to trigger it?

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26) Would you say that this is the most common trigger? If not, what is?

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27) Out of 10, what proportion of all skin picking that X shows seem to be caused by the trigger that you have identified?

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28) Does the trigger that you mentioned always result in skin picking?

Yes No

***If no*, out of 10, how often does the trigger that you mentioned result in a period of skin picking?**

.....

What happens on the occasions that it does not trigger skin picking? What is different about these times?

Leave free response initially

.....
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.....

Prompts:

- Is the trigger definitely the same?
- Are there different people present?
- Is X's mood different in some way?
- Does X do something that means that they are not thinking about the trigger or do not notice that it occurs?
- Do you do anything to prevent the skin picking from occurring?

29) We have established thatis a common trigger to X's skin picking. Are there other triggers?

Yes No

If yes, list below in order of most frequent to trigger skin picking.

- 1).....
- 2).....
- 3).....
- 4).....

30) What percentage of the time does X look at what they are picking?

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31) When X is skin-picking do they show any signs of pain?

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32) Are there times when X skin picks even when you think that they don't want to do it?

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33) What does X say about their skin picking?

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34) Does X try to hide their skin-picking?

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35) Is there anything else about skin picking that you would like to mention that has not been asked about?

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