

1 **Growing up with juvenile vulvar lichen sclerosus, the experiences and care needs of adult**
2 **women with lichen sclerosus since childhood: a qualitative exploration**

3 **Running head:** Qualitative study of the experience of women with history of JVLS
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1 females.^{4,6} We speak of juvenile vulvar lichen sclerosus (JVLS) when the disease occurs in childhood or
2 adolescence.¹⁵ Despite the fact that research on VLS and JVLS has increased in recent years, major
3 knowledge gaps remain.^{15,16}

4 The burden of having a chronic vulval skin condition such as VLS has a negative impact on quality
5 of life (QoL).^{6,14,17-20} Several qualitative studies have been conducted to gain a better understanding of
6 the experiences of women with VLS, though focusing on women diagnosed as adults, showing that the
7 needs of women with VLS are currently not sufficiently met by the healthcare system.^{7,21-26} Little is
8 known about the experiences and impact on the lives of children or adolescents with JVLS and their
9 caregivers nor the repercussions in adulthood, including the (sexual) development and obstetric
10 experiences which will mostly take place many years after the initial diagnosis of JVLS.¹⁵

11 The aim of this study is to gain understanding of the experiences of women with a history of
12 juvenile VLS (JVLS), regarding the impact of the disease on their personal lives, and their experiences and
13 needs regarding care and guidance during childhood, adolescence and adulthood.

14

15 MATERIAL AND METHODS

16 *Study design*

17 A qualitative study was designed to gain an in-depth understanding of what females with a history of
18 JVLS experience from time of diagnosis in childhood onward. Individual interviews were chosen over
19 focus groups, as they are considered most appropriate for exploring sensitive topics.²⁷

20 Reporting followed the Standards for Reporting Qualitative Research.²⁸ The Institutional Review Board of
21 Erasmus MC approved the study (MEC-2019-0474, amendment A-0004 NL63335.078.19 v11).

22

1 ***Selection and recruitment of participants***

2 The study group was recruited from the group of adult women with histologically confirmed JVLS in the
3 Netherlands who were aged 18 years or younger at time of diagnosis and fluent in the Dutch language
4 and who had participated in a previous study.^{1,20} All eligible women (n=79) were sent an information
5 folder by email and post and invited to participate, aiming for maximum variation. Twenty-nine women
6 gave their written informed consent, and interviews were completed with 27 women. Travel expenses
7 were reimbursed.

8 ***Data collection***

9 The participants visited the out-patient department of the Erasmus University Medical Center from June
10 to October 2022. A clinical examination of the vulva was performed simultaneously by three experienced
11 vulvar clinicians (CLMvH or KMGJW, BM and MJtK-B). A clinical assessment of disease severity was made
12 and shared with the participant who was given the opportunity to ask questions.^a An audio-recorded
13 interview was then conducted in Dutch (BM, MJtK-B). If the participant wished, an accompanying family
14 member joined the interview. Duration of the interviews ranged from 15-55 minutes. An interview guide
15 (Supplement 1) was followed. Investigator triangulation was used to reduce bias for both data collection
16 and data analysis by having two researchers perform and analyse the interviews.²⁹ The patient
17 characteristics were collected and stored using the LIMESURVEY and GEMSTRACKER software.

18 ***Data processing and analysis***

19 The audio-recordings of the 27 interviews were transcribed verbatim and anonymised. Age at time of
20 biopsy, current age, ethnic background and education were categorised to ensure anonymity. The
21 transcripts were analysed using the qualitative data analysis software NVivo version 12 (QRS

^a Reporting of physical findings <paper accepted and being processed for publication in the Journal of Lower Genital Tract Disease>

1 information given by the health care professional (HCP), corroborated by several mothers who joined the
2 interviews.

3 *iv. Effect of sharing experiences with others.* Women who were able to talk about their condition with
4 their caregivers, friends or partners often felt supported and understood. For others shame and taboo
5 formed a barrier to discuss their condition. Contact with fellow sufferers had a positive influence for
6 some, while for others their worries were augmented by information and horrific stories shared on social
7 media.

8 **II. Finding one's way in care and guidance, i.e. navigating the patient journey**

9 While navigating care and guidance, women often felt hindered by several barriers as described in the
10 five identified subthemes, illustrated by the quotes in Table 5.

11 *i. Knowledge gaps among HCPs.* The participants felt that knowledge gaps of HCPs led to delays in
12 diagnosis and care. This also led to feelings of being misunderstood and inadequate guidance around life
13 events, e.g. being cared for by a midwife who is completely uninformed about VLS. Whether or not the
14 HCP was knowledgeable influenced how women perceived their disease, and some expressed
15 sometimes feeling misunderstood. Furthermore, women explained that the physician did not always
16 check if the child and her parents understood the information provided.

17 *ii. Lack of continuity in ongoing (follow-up) care* was often reported and perceived as a shortcoming.
18 Sometimes the patient was told by the HCP that follow-up was no longer necessary (contrary to current
19 guidelines). Participants described that their caregiver or they themselves ended the contact because of
20 the absence of complaints, loss of interest during puberty or adolescence, or not realising that
21 continuing care was advised.

22 *iii. Lack of life-stage adjusted and future-oriented information provision* at different stages of growing up
23 was experienced as a shortcoming by some women, while others were content with the information

1 DISCUSSION

2 We report on a qualitative study of adult women who were diagnosed with VLS during childhood or
3 adolescence. The analysis identified three major themes, namely, varying impact of living with (J)VLS,
4 navigating the patient journey with care and guidance, and, finally, the need for patient-tailored care
5 involving appropriate and compassionate care and guidance. The experiences of the child, adolescent
6 and adult with JVLS are influenced by their coping strategies and their social context.

7 **Varying impact of disease**

8 The present study shows that while the experience of these women in many aspects concurs
9 with adult onset VLS regarding the impact of the disease, there are also some differences. In previous
10 qualitative research on women diagnosed with VLS at an adult age, the participants were often recruited
11 through social media and special interest groups, and often older. Common themes in those studies
12 were: dealing with the chronic aspect of VLS, feelings of taboo and shame and the consequent feelings of
13 loneliness and isolation, and disruption of sexual functioning.^{7,21,22,24,26,34} In addition to those themes, our
14 young participants (median age 29 years) often focussed on dealing with the disease in daily life and
15 their own (lack of) knowledge about VLS. Coping strategies had been developed at an early age, ranging
16 from denial to acceptance or even incorporating the VLS into their own sense of being, as had been
17 described in children with severe chronic skin disease.^{35,36} De Maeseneer et al. performed a study among
18 children with severe chronic skin disease, and ascribed this phenomenon to the so-called 'disability
19 paradox' of Albrecht and Devlieger.^{35,36} This might also explain the gap between the perceived quality of
20 life and the observed severity of VLS activity among our study group.^c

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^c Same reference as in footnote a and b.

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Table 1. Individual participant characteristics (n=27)

Participant's number in quotes	Age at time of interview (years)	Age at time of biopsy (years)	Ethnic/cultural identity	Educational status	Sexual identity	Having ever given birth	Status of VLS at time of interview*
1	30-39	2-5	Indonesian Dutch	Post-secondary vocational education	Heterosexual	Yes	Moderate
2	20-29	6-12	Indonesian Dutch	Post-secondary vocational education	Not reported	No	Not active
3	<20	6-12	Dutch	Higher professional education	Heterosexual	No	Not active
4	30-39	13-18	Dutch	Post-secondary vocational education	Heterosexual	Yes	Moderate
5	20-29	2-5	Dutch	Higher professional education	Not reported	No	Mild
6	20-29	6-12	Dutch	Post-secondary vocational education	Homosexual	No	Moderate
7	20-29	6-12	Dutch	University degree	Heterosexual	No	Mild
8	20-29	6-12	Dutch	University degree	Heterosexual	No	Mild
9	20-29	6-12	Turkish Dutch	Post-secondary vocational education	Heterosexual	No	Mild
10	30-39	13-18	Dutch	Post-secondary vocational education	Heterosexual	Yes	No evident LS
11	20-29	6-12	Turkish Dutch	University degree	Heterosexual	No	Not active
12	20-29	13-18	Dutch	Post-secondary vocational education	Heterosexual	No	Not active
13	30-39	6-12	Dutch	Post-secondary vocational education	Heterosexual	Yes	Not active
14	30-39	6-12	Dutch	Higher professional education	Heterosexual	No	Not active
15	<20	2-5	Dutch	Higher professional education	Heterosexual	No	Moderate
16	20-29	13-18	Dutch	Post-secondary vocational education	Heterosexual	Yes	Mild
17	20-29	13-18	Dutch	University degree	Heterosexual	No	No evident LS
18	20-29	6-12	Dutch	University degree	Not reported	No	Mild
19	40-49	13-18	Dutch	University degree	Heterosexual	Yes	Severe
20	30-39	2-5	Dutch	Higher professional education	Heterosexual	Yes	Not active
21	20-29	2-5	Mixed Ethnic Background	Higher professional education	Bisexual	Not reported	Severe
22	20-29	6-12	Dutch	Higher professional education	Heterosexual	No	Moderate
23	30-39	13-18	Dutch	Secondary education	Heterosexual	No	Moderate
24	20-29	13-18	Dutch	Post-secondary vocational education	Homosexual	No	Mild
25	30-39	2-5	Dutch	Higher professional education	Heterosexual	Yes	Moderate
26	20-29	13-18	Dutch	Higher professional education	Heterosexual	No	Mild

27	30-39	6-12	Dutch	Higher professional education	Heterosexual	Yes	Not active
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1 *Based on physical examination prior to interview.

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3 **Table 2. Participant characteristics, adult women with JVLS (n=27)**

PARTICIPANT CHARACTERISTICS	N
Age at time of biopsy (years)	
2-5 (preschool child)	6
6-12 (child)	12
13-18 (adolescent)	9
Age at time of interview (years)	
20-29	15
30-39	10
40-49	2
Ethnic/cultural identity	
Dutch	22
Non-Dutch or mixed Ethnic Background	5
Educational status	
University degree	7
Higher professional education	9
Post-secondary vocational education	9
Secondary education	2
Sexual identity	
Heterosexual	21
Homosexual	2
Bisexual	1
Not reported	3
Obstetric status	
Never pregnant	17
Ever pregnant	10
Status VLS at time of interview*	
Active	
Mild	8
Moderate	7
Severe	2
Non-active with residual signs	8
No evident LS	2

4 *Based on physical examination prior to interview.

5 Abbreviations: JVLS juvenile vulvar lichen sclerosus; VLS vulvar lichen sclerosus

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Table 3. Outline of themes in care and guidance of women with Juvenile Vulvar Lichen Sclerosus

I. Varying impact of living with JVLS
i. Impact on women's personal lives and daily activities
ii. Emotional impact of receiving the diagnosis as a juvenile
iii. Feeling insufficiently equipped with knowledge about (J)VLS
iv. Effect of sharing experiences with others
II. Finding one's way in care and guidance, i.e. navigating the patient journey
i. Knowledge gaps among health care professionals
ii. Lack of continuity in ongoing (follow-up) care
iii. Lack of life-stage adjusted and future-oriented information provision
iv. Inadequate guidance around life-events
v. Insufficient monitoring of determinants of therapy adherence
III. Need for patient-tailored care involving appropriate and compassionate care and guidance
i. Age-appropriate and life-phase adjusted information provision and knowledge at all levels of society
ii. Patient-tailored and compassionate care and guidance

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2 **Table 4. Theme: Varying impact of living with JVLS**

Subthemes	Quotes
Impact on women's personal lives and daily activities	
Complaints in childhood and adolescence	'I can't remember much, only that there was prickly and burning sensation and that I avoided bowel movements. In the evenings I asked to sit in the bathtub and the burning and prickly feeling would go away after that my mother put ointment on. I usually slept without knickers but I scratched it completely open because of the itching.'
Difficulties in daily life	'For a long time all went well. But when I started having my periods things went wrong, sanitary towels didn't work, I was always wet; but by trying different towels and changing often I found my way. Sometimes I had to use 8 towels a day. It was expensive, I even had to change pads at night.' 'The only thing I can think of is, for example, with cycling, that was the only problem, that I often had complaints when on my bicycle, and at a certain point I got a special rounded shaped saddle meant for wearing a skirt.'
Emotional impact of receiving diagnosis as a juvenile: (from shame and denial to complete acceptance)	
Feeling normal vs. different	'As I child, you want to feel you are normal and when you're lying there, you really feel like this is not normal. Other kids my age didn't have to go through that. So that's why it was a trauma every time, even before I had to go to the appointment itself. At a certain point my mother didn't tell me that we were on the way to the hospital.' 'In high school I became aware in biology lesson. We had pictures in the textbook and then I saw that it looked different to mine. So I thought "oh yeah, I'm sick".' 'As far as I know, it all looked normal, no two are the same. So, I never thought "blimey, it looks strange" or that I felt less or more than another (because of it).'
Self-blame	'I thought that I had caused it myself, that I shouldn't scratch...I thought it was my own

	<p>fault. Maybe if I had known that there could be something wrong I would have gone to the doctor sooner.'</p>
Dealing with the diagnosis	<p>'Moisturising is important, but otherwise....just take it as it is, just moisturise and accept. Being dramatic is just wasted time.'</p> <p>'In itself, sexual intercourse is fine, only, if you touch the clitoris with a finger, um, I don't know, it's just not really a nice feeling for me. It feels like a wound being rubbed. Yes, that, and that used to be different of course. So yes, I notice a difference. I hardly have any problems, maybe four times a year.'</p> <p>'I think I didn't even tell my friends, I can't remember, I think that I felt alone....and that I went through it on my own. That's weird, that you are all alone your whole life. Then you're your own discussion partner, your own psychologist, your own coach. So that's in your own head, from 5 years old on. (Interviewee becomes emotional).'</p> <p>'When it (the LS) returned when I was 12 or 13 years old I completely panicked.'</p> <p>'Straight away I thought I wouldn't be able to have children and that I would gradually close-up completely. My sister said "I'll be a surrogate mother for you." That's how far I was thinking.. although at that time I wasn't even thinking about having children yet. Now I realise, blimey, I could have saved myself a lot of sadness and fear if I had known how it really was, something like that.'</p>
Feeling insufficiently equipped with knowledge about (J)VLS	
	<p>'I still don't dare to go to the toilet anywhere. I can't. I think to myself, "maybe it's dirty, or I'll catch something, an infection." I'm afraid of a bladder infection. So I've had days, days when I've held my urine up for a very long time.'</p> <p>'Yes, at the beginning of my pregnancy I didn't want to apply ointment because I wanted to avoid harming the baby. But at a certain point the itching was so bad that I just had to apply ointment to calm it down.'</p>
Effect of sharing experiences with others	
	<p>'When I was younger I found it more difficult, but now I live in a house with four female roommates, they know about it and I can talk to them about it. I could talk to my mother about it, she understood and that was perfect.'</p> <p>'I knew that I had it, I didn't want to know, didn't want to have it, and I didn't talk about it to anyone. In puberty my interests were not at all there. I'd rather not have it and acted as if it didn't exist.'</p> <p>'I visited the Facebook group online, but those are such scary stories, I think, "Is this what I want?" Because I'm young maybe progression is slower, so that I'm lucky. So, yeah, do I really want to know everything that's awaiting me?'</p>

	long as I use the ointment almost every morning, then I think for that moment, “oh dear”, and I find it nice that I can ignore it the otherwise.’
Regular follow-up consultations	‘And I don’t think I had any more check-ups. So that makes it easy be less attentive, so each year I think, “no, not this year”. Just like I’m thinking right now, “o.k., maybe I should go.” Somehow I think that a bit of pressure helps.’
Entering a new phase of life	‘I think I did have a phase when I was more negligent about applying ointments, and when you’re young you don’t have all that many ideas about it.’
Involvement caregivers (social context)	‘Your background plays a big role in that. To what extent did your parents include you in what was going on. My parents were given an ointment that we had to keep applying, only there was some miscommunication. My mother thought that we just had to finish the one tube, but the doctor meant life-long. She feels guilty about both these things, about not knowing enough, but especially that she did not realise she had to continue with the applications.’
Understanding of VLS information by patient and caregivers	‘My ointment is lying there, but I don’t apply it too often because I think, the less sometimes, the better. Then, anyway, that’s what I thought. So a tube of ointment would last maybe 2 to 3 years.’ ‘I know that I should use the ointment, but with me, well it’s just that I’m afraid of the Dermovate, you know, that hormone ointment, that if I use it I’ll get wounds. I’m so afraid of that happening.’
Protective effect long-term consequences	‘I did start with ointment application, not so much for the present, but I use maintenance for prevention for when I’m older.’

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2 **Table 6. Theme: Needs for patient-tailored care involving appropriate and compassionate care and**
3 **guidance**

Subthemes	Quotes
Age-appropriate and life-phase adjusted information provision and knowledge at all levels of society	
	‘Maybe it would be good to speak to the adolescent alone. Because a teenager doesn’t really want to discuss everything with their parents. At least I didn’t want to. Maybe some people do.’
	‘What really helped me was that I looked on the internet. One of the first things I saw was an ‘influencer’, who had also been diagnosed and she had a lot of female followers, maybe between 18 and 28 years old.... In her video she talked frankly about what her symptoms were and that the GP thought it was a yeast infection. When I read that I recognized this, and all the posts of young women who had the same experience. So that really helped me and I also found it refreshing. Because all the information that is available and all the research is in such difficult medical language.’
	‘Yes, I’m sure that information in my native language would have helped. Even if the name of the disease is the same, if you are given a brochure or written flyer that’s in your own language you can absorb it better, rather than superficially skimming through it.’
	‘Though I know one might think that a 13 year-old and 16 year-old are of similar ages, the 13 year-old is more likely to think, “it doesn’t matter much if I don’t use the ointment sometimes”, while as a 16 year-old you’re more mature...so the discussion

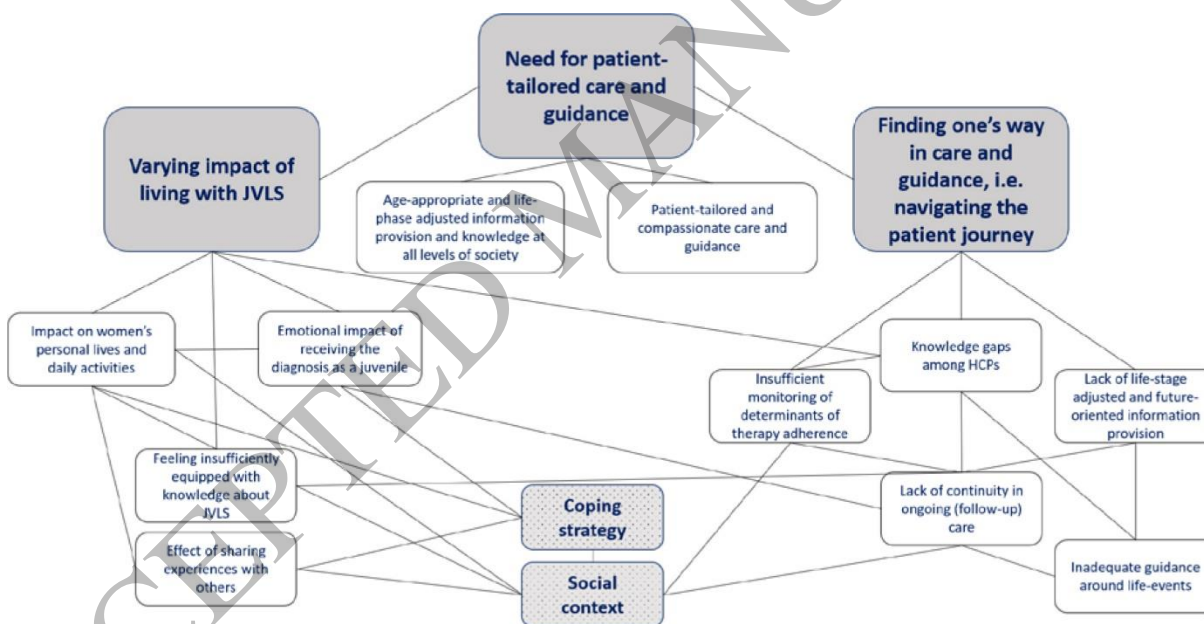
	<p>that one has with their doctor at 13 should be repeated at 16. I don't know if that is attainable, but the discussion should be repeated, say, every four years or so.'</p> <p>'Actually, I was usually only asked how many symptoms I had, how often I applied ointment, if I had any pain or complaints with daily living, or if I had any difficulties. But I think that from a certain age onwards maybe then you should be asked more directly about sex partners. Not much was ever asked about that. They asked if I was sexually active, but then didn't ask any further.'</p> <p>'That would have been better if someone had told me, "That seam in your underwear may be unpleasant". For trousers they did tell me that if they're too tight it would rub and be uncomfortable. It would have been better if someone had taken the trouble to tell give me advice in the choice of underwear, something like that.'</p> <p>'I do think that for children it's better not to make an issue of it, just name it and move on ... In daily life I didn't have many problems with it, so I think, don't make it a bigger problem than it is.'</p> <p>'Through this questionnaire I learned that there is platform for LS, I really didn't know about that. So I think that it is great that there's this platform, and maybe I didn't know about it because I've been going to the doctor for so long, nobody thought to tell me.'</p>
General education	<p>'But maybe they should put information about it in magazines for parents, a few that are popular, with information about if you child is scratching their bottom, what you should know. Websites for parents with questions about their kids are full of information, they lead you to the websites of those magazines.'</p>
Patient-tailored and compassionate care and guidance	
	<p>'What I remember is that when my gynaecologist told me I could go to the GP for my check-ups I told her that I didn't think that was really a good idea. I felt that a GP has much less understanding because they rarely see it. So I chose to continue having my check-ups with the gynaecologist.'</p> <p>'Nobody ever asked before now, "How do you feel about this?" No, they never asked that. I think that for children the psychological aspects are important. But nobody looked at that.'</p> <p>'As a child, and in the years that followed I had the same gynaecologist every visit, and then you get to know each other. So I didn't mind it so much, and (when I was older) I just went on my own without my parents, of course.'</p> <p>'Since last year I visit a gynaecologist that, personally, I prefer. Maybe because they're new, and want to get to know me. She asked much more thoroughly including how it was for me [to have the LS] and that was much more pleasant than previous experiences.'</p>

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1 **Table 7. Points of attention during every consultation with a patient with JVLS**

Social context
Coping strategies
Determinants of therapy compliance
<ul style="list-style-type: none"> ❖ Absence or presence of complaints ❖ Experiences with ointments and creams ❖ Regular follow-up consultations ❖ Entering a new phase of life ❖ Involvement caregivers (<i>social context</i>) ❖ Understanding of VLS information by patient and caregivers ❖ Protective effect long-term consequences
Relevant personal questions the patient has
New insights

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5 **Figure 1. Thematic network of main- and subthemes and influencing factors regarding the**
6 **experiences of women with a history of JVLS and their needs for care and guidance**

7 *The interrelationships between the (sub)themes are indicated by connecting lines.*

8 *Figure 1*
160x104 mm (DPI)

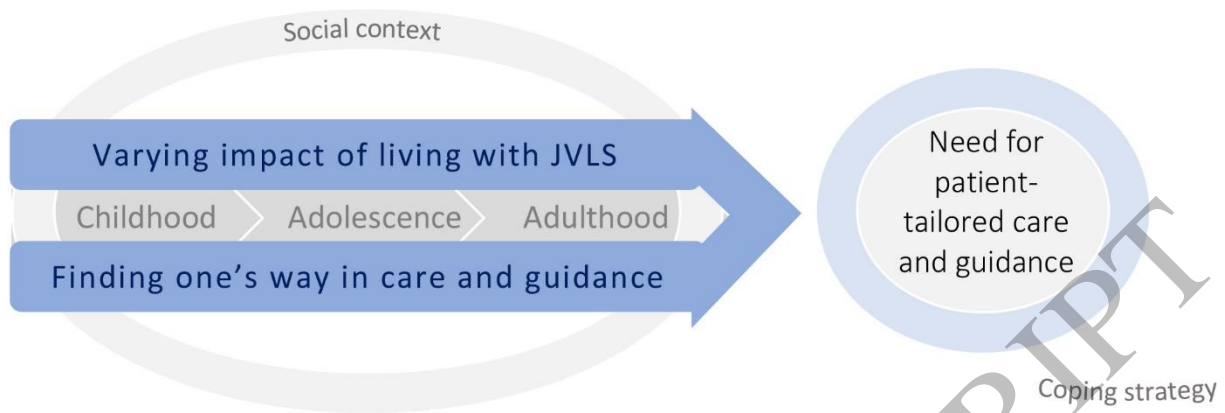


Figure 2. Schematic overview themes: Experiences of women with a history of JVLs and their needs for care and guidance

The three phases of life (left, grey inner arrows), the two main themes (left, dark blue outer arrows), the two influencing factors (left, grey outer circle), resulting in the third, and overriding main theme (right, grey inner circle).

1
2
3

Figure 2
160x74 mm (DPI)

ACCEPTED MANUSCRIPT