LOU'S QUESTIONNAIRE

User Guide

lapproche

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RECHERCHES SUR LES JEUNES AIDANTS

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Foreword

Lou's Questionnaire (QL) is the first French-language, self-administered, illustrated tool designed to help identify school-age children (7 to 12 years old) who are likely to be a caregivers, or are in a caregiving situation. It was developed and pre-tested as part of the *Étude sur les élèves et les étudiant·es soutenant un·e proche au Québec* (ESPQ; *Study of students caring for a close relative in Québec*), a research project mandated by the Québec Ministries of Education and Higher Education. This vast project, leaded by Aude Villatte and the LaPProche Laboratory at the Université du Québec en Outaouais (UQO) team, aims to document the proportion, characteristics and needs of young carers in Québec's educational institutions. It also includes a component to raise awareness of the realities of student and family caregiver situations.

This guide provides complete instructions on the administration and interpretation of the QL. It includes tips for intervention, as well as ethical considerations to be respected throughout the process. It is recommended to read this guide before using the QL.

Acknowledgments

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Introduction

Young carers: a public health issue

The Lou's Questionnaire (QL) responds to a growing concern in Québec regarding Young Carers (YC). In 2021, a national policy was put in place for caregivers, emphasizing the need to focus on emerging phenomena such as YC. Caregiving is now recognized as a public health issue due to its high prevalence and significant impact (Government of Québec, 2021a).

In Québec, as elsewhere in the world, many children regularly support someone close to them who is ill, aging, disabled or in difficulty. In most cases, this person is a parent. This caregiving role, which is added to their other daily activities, can have significant impact on their lives, particularly on their schooling.

However, the identification of young carers is complex, particularly among children, due to the lack of knowledge of this phenomenon and the difficulty of self-identification among the young people themselves. The lack of tools specifically designed for YC at primary age may also contribute to their invisibility.

What is a young carer (YC)?

YC are individuals under the age of 25 who provide care or support to family members or loved ones with physical, mental, intellectual or sensory disabilities. This role may involve looking after family or friends or stepping in to fill the caregiving gap when a parent or guardian is unavailable (Proche Aidance Québec, 2021, p.4).

The support provided by YC may vary depending on the nature and extent of the difficulties faced by the person in their care and the closeness of the relationship. This includes domestic tasks, personal and medical care, emotional support or administrative responsibilities. The support provided may be continuous or occasional, short or long term, and is provided on a non-professional basis (Government of Quebec, 2021b).

Impact on affected youth and the importance of early identification

Taking on the role of caregiver can offer personal and relational benefits, but it also comes with significant challenges. YC are often at risk for physical and mental health problems, as well as difficulties with relationships, school, and family. The earlier a child begins to take on these responsibilities, the more damaging the negative effects can be (see Appendix A - Risk and Protective Factors).

Early identification of these children is critical, as some may assume caregiving responsibilities as early as age five. On average, young people report beginning to assist a loved one by age 10, with the scope of responsibilities typically increasing with age (Becker, 2021).

The ability to identify these children as early as elementary school would make it possible to provide timely, appropriate support to the young people concerned and ensure that those who are at risk of assuming significant responsibilities have access to the resources and conditions necessary to support their healthy development (Aldridge, 2018; Becker, 2021).

QL design and pilot evaluation

The design of the QL was based on the scientific literature on the identification of YC (e.g., the MACA-YC18: Joseph et al., 2019; French version: Chevrier et al., 2022) and recommendations on the quality of screening tools for young children (Bergeron et al., 2013; Dobrow et al., 2018).

The QL is visual, user-friendly and designed specifically for elementary school-aged children. It takes into account their developmental abilities, including their language skills and ability to think abstractly. The visual format enhances comprehension and engagement, while its computerization makes the completion experience easy and more enjoyable. However, depending on the child's age and ability, some may need additional support to fully complete the QL.

In the spring of 2024, the LaPProche conducted a pre-test with 34 children aged 7 to 12 to assess the comprehension, interest, safety and feasibility of the French version of the QL. The results of this study showed that the QL is generally well understood and appreciated by children and is considered safe. Some elements were identified as needing adjustment, resulting in improvements to the current version of the questionnaire.

Please note that the QL was originally developed and tested with children in French. The English version is only a full translation of the original. It is therefore impossible to claim that the English version is of the same quality as the French version.

Lou's Questionnaire (QL)

Objectives

The main objective of the QL is to identify children at risk of experiencing a family caregiving situation, in order to allow for rapid intervention, if necessary. The secondary objective of the QL is to raise awareness among school staff and intervening staff about the existence of children with caregiving roles from primary school onwards and their specific needs.

To this end, the QL allows for the collection of self-reported information on the child's profile (e.g., gender, age, well-being), on the presence of people with difficulties in their families, and on the type of support they provide to their family.

The QL is not a diagnostic tool. In fact, it does not definitively determine whether a child is a caregiver. Rather, it allows us to identify children who appear to have characteristics of a young caregiver (e.g., numerous or significant responsibilities, tendency to forget one's own needs in favor of others) or who are at risk of becoming one (e.g., a young person with a relative who has a difficulty), while also highlighting children who may need support in the short or medium term, whether because of a caregiving role or for other reasons.

Lou

Lou is a gender-neutral fictional character designed to make the questionnaire more accessible and engaging for children. Lou guides children through the different sections of the questionnaire by inviting them to answer the questions, making the experience more interactive.

The QL also includes a narration feature that reads the questions aloud and includes optional background music to make the process more playful and enjoyable.

Target population

The QL can be completed by a child between the ages of 7 and 12 who is sufficiently proficient in French and English to be able to read and understand simple texts. In addition, the child must not meet the clinical criteria for a diagnosis of intellectual disability in order to complete the questionnaire optimally.

QL terms of use

The QL is a self-administered tool to be completed online, with an estimated completion time of 15 to 30 minutes. It must be completed under the supervision of a qualified person who works with children, such as school staff (teachers, specialized educators), health and social services networks and the community. These people, because of their proximity to children, can play a key role in identifying family caregiving situations.

Any adult with training in college or university intervention, or equivalent, is authorized to invite the child to complete the questionnaire and to assist him or her in this process. Although the child completes the questionnaire alone, the adult is encouraged to be nearby to provide technical assistance, such as answering questions, clarifying terms, helping with online navigation, or reading the questions aloud if necessary. However, to minimize social desirability bias, it is important that the child provides his or her answers without having to communicate them to the adult.

The questionnaire can be completed by several children at the same time (e.g., in a classroom), provided that each child has access to a computer, headphones, and a place that guarantees the confidentiality of the answers.

We recommend that the questionnaire be administered during the regular school year, avoiding vacation or holiday periods (e.g., spring break, Christmas break). The questionnaire can be administered several times a year, with a minimum of 3 months between each administration.

Logistical and ethical considerations

When administering the QL, it is essential to ensure a respectful and safe experience. Here are some elements and tips to consider:

- ***Familiarize yourself with the QL and its user guide.*** Take the time to read this guide and explore the QL online to fully understand the administration steps and the questionnaire content.
- ***Consent and approval.*** Obtain the free and informed consent of parents or guardians by clearly explaining the purpose and nature of the questionnaire. Also, ensure the child's consent by explaining that he or she can choose to participate or not, and that he or she can stop the questionnaire at any time without consequence.
- ***Confidentiality of responses.*** The information collected will be kept confidential. The QL is hosted on the UQO LaPProche website and no data is recorded by or accessible to the research team. You cannot save the responses, but you can download or print a summary of the results. Be sure to do this before closing the page. See the Terms of Use on the LaPProche website for more details.
- ***Choose a quiet and comfortable place.*** Choose a place where children will feel comfortable and safe, away from distractions and noise, to help them concentrate.
- ***Prepare the necessary materials.*** Make sure you have the online questionnaire, as well as a computer or tablet, with a mouse and headphones, if necessary. A mat may also be helpful for greater comfort.
- ***Establish a bond of trust.*** Before you begin, take the time to introduce yourself and talk with the child. An icebreaker activity may help them feel more comfortable.
- ***Reassure the child.*** Explain that the questionnaire will be used to better understand what they are experiencing at home and at school. Assure them that there are no right or wrong answers, that they can choose not to answer certain questions and that they can take as much time as they need. Also assure the child that their responses will remain confidential and praise them for their efforts.

- ***Be sensitive to the child's signals.*** Observe the child for signs of fatigue, stress or disinterest. If necessary, offer a break before continuing. Listen to what the child is experiencing or expressing. Some questions may trigger emotions such as embarrassment or sadness. Offer support if needed. Also explain to the child what will happen after the questionnaire is completed. The last question asks how the child feels now, which can provide insight into their emotional state. Observed behaviours can also provide useful information for interpreting the results.

- ***Ethical and legal compliance.*** Adhere to your professional standards, code of ethics and ethical practices. Ensure that all actions comply with legal and professional requirements. If there are concerns, such as signs of risk or danger to the child, inform the parents or guardians and provide them with appropriate resources to intervene appropriately. In carrying out their duties, adults working with children must immediately report all situations covered by the Youth Protection Act to the Director Youth of Protection, regardless of the context and the people involved (persons in authority, peers, family members, etc.).

QL content

Age and siblings

The first two questions are about the child's age and the presence of siblings. This information makes it possible to avoid asking questions about siblings for an only child and to contextualize the results in terms of family and developmental issues. For example, a high score may be considered all the more worrisome if it is obtained by a 7-year-old child - as opposed to an older one - given that responsibilities tend to increase with age. In any case, the results must be interpreted according to each child's specific abilities and situation.

Frequency of tasks performed to help

This section explores tasks the child has recently performed to help someone in the family. The 21 items provided represent tasks that YC may be asked to perform. Each statement is accompanied by an illustration to clarify the question. The child indicates how often he or she has performed each task by choosing from the following options Never, Sometimes, or Often. The child also has the option of not answering the questions, and this lack of response is noted in the summary of results.

Example item

Clean your room

○ I never do that.
○ I sometimes do that.
○ I often do that.

The questions are grouped into six main categories of support tasks:

Household activities	• Cleaning your bedroom • Cleaning rooms other than bedroom • Washing dishes or fill/empty dishwasher • Preparing meals
Household Management	• Doing small jobs and repairs • Doing the grocery shopping or errands alone • Lifting or carrying heavy objects
Financial and practical management	• Filling out adult forms • Helping someone speak or understand
Personal care	• Helping someone get dressed or undressed • Helping someone wash themselves • Helping someone take a bath or shower • Helping someone get around
Emotional support	• Keeping someone company • Comforting someone • Checking on someone to make sure they are okay • Listening to someone talk about their problems • Suggesting activities to keep someone busy or entertained
Sibling care	• Taking siblings to school, daycare or activities • Caring for siblings when an adult is present • Caring for siblings when an adult is not present

These last three questions on sibling care appear only if the child indicates that they have a brother or sister.

To calculate the score, each statement is evaluated according to the following scale:

Never = 0 point
Sometimes = 1 point
Often = 2 points

The total score for the child's caregiving activities is calculated by adding the subscores for the six categories. The maximum possible total score for children who report being a member of a sibling group is 42 points (21 items shown), while for an only child it is 36 points due to the three missing items on sibling care (18 items shown).

A higher score indicates a higher level of care or support activities:

0 = No task
1 to 6 = Low frequency
7 to 10 = Moderate frequency
11 to 13 = High frequency
14 and above = Very high frequency

Reminder: Although the calculation of the scores is the same for all children regardless of age, the interpretation of the scores must take into account the child's developmental abilities and situation.

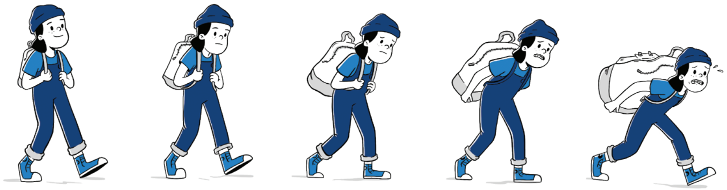
Health of the child's friends and family and the support provided

This section explores the health of the child's close friends and family and the support the child believes they provide to them. For all these questions, the child can choose not to answer.

The child first indicates whether someone close to them is often sick or needs help. If the answer is Yes, the child answers three additional questions to:

1. Identify the person.
2. Indicate if they are often worried about this person.
3. Specify whether they regularly provide help to this person.

If the child indicates that they help this person, they rate the difficulty of this support on a pictorial scale ranging from 1 (easy) to 5 (extremely hard).



Caution: Many YC are not fully aware of the extent of the support they provide to their loved ones. Therefore, interpretation of the QL should not be based solely on the child's responses to these questions. For example, a child may report that they are often worried about a family member without providing direct support. This does not necessarily mean that the child is not playing a caring role, as support may take more subtle or less visible forms.

General state

This section provides a general portrait of the child through a series of questions.

The child first identifies his or her gender, grade level, country of origin, and who he or she lives with most of the time. These data make it possible to analyze the results taking into account the child's socio-demographic situation.

The questionnaire then explores discrete helping behaviors, a type of support often observed among YC, such as the tendency to keep one's problems to oneself so as not to worry the family, or the fact of solving one's difficulties alone.

Finally, the child's state of health and well-being is explored through a series of illustrations representing different states (tired, nervous, sad, in good shape, etc.). The child also rates his or her general health on a scale of 1 to 5, from *Bad* to *Excellent*, and his or her immediate feelings at the end of the questionnaire on a scale represented by Lou's facial expressions.

This information makes it possible to quickly identify signs of distress in order to take appropriate action, thus helping to prevent risky behaviors and the deterioration of certain family and personal situations.

Comment

Finally, there is space for the child to share his or her thoughts, feelings, or questions. He or she can also choose to comment verbally if he or she prefers.

Summary of results

The QL generates a summary of the results at the end of the assessment. This document can be saved as a PDF or printed as needed. It is recommended that an adult supervise the review of this section as it is specifically designed for adult interpretation.

While the QL is not a diagnostic tool, it does help identify children who may be at risk or already in care. The responses provide a broad overview of the child's experience, including the tasks they perform, the support they provide to a sick family member, and their own overall health and well-being.

The summary also provides prompts for **specific responses**. These prompts are intended to draw the adult's attention to responses that may indicate specific concerns or signs of stress or overload in the child (e.g., lack of time for leisure activities, difficulty having fun with friends).

Other indicators, such as the frequency of tasks performed or the assumption of responsibilities inappropriate for the child's age, are also reported. These signals help to better understand the child's situation and to take appropriate action if necessary.

Depending on the responses, a **final message** is generated to guide the next steps. If certain responses raise concerns (e.g., indicators of dissatisfaction), an in-depth discussion may be recommended. If the results indicate a score between moderate and very high regarding the frequency of tasks or the presence of a sick relative (who the child perceives as supportive or not), the message includes the following statement "The child may take on a caregiving role and experience certain challenges related to these responsibilities". This indication is intended to signal the need for more detailed assessment and the possible implementation of appropriate support measures.

When interpreting the results, it is important to consider the child's age, developmental level, and life context. If several alerts are noted, a discussion may be considered. It should be remembered that the purpose of the questionnaire is not to determine whether the child is a caregiver or not, but rather to identify situations that may require special attention.

The summary provides an overview of the child's experience and is a starting point for guiding necessary interventions. It is important not to jump to conclusions - the results must be interpreted with caution and placed in the overall context of the child's life. Further clinical assessment may be needed to fully understand the child's situation and provide appropriate support.

Tips for discussing with the child

This section provides guidance and suggestions for structuring and, where appropriate, conducting discussions with the child.

Before you begin the discussion, be clear about your goals: to understand the child's experiences and circumstances, to identify his or her needs, and to provide appropriate support. Make sure the child feels comfortable and safe to share his or her thoughts. Explain the purpose of the discussion in a simple, age-appropriate way so that the child understands why this discussion is important according to the QL.

Some children may be reluctant to share information about their family for fear of getting into trouble. Reassure them that the conversation is confidential and that you will only share information if there are concerns about their safety (or the safety of others), their development, or to provide additional support.

To begin the discussion, ask questions that encourage the child to talk freely about their experiences and feelings. These questions should be asked in a way that is sensitive to the child's responses to the QL and should be asked in a safe environment, so that the child feels comfortable answering without feeling judged or overwhelmed by the situation. Examples of probing questions include:

- ***Do you help someone at home? Who do you help? How do you help them?***
- ***Do you sometimes do things around the house that adults normally do? What do you do?***
- ***Do you sometimes take care of someone when they are not well? What do you do to help them when they are sick?***
- ***When a member of your family is not well, what do you do? Do you stay with them or do something to make them feel better?***
- ***Are there times when you worry about someone at home? Why do you worry about them?***
- ***Do you sometimes feel like you have to take care of things that your parents or an adult can't do? What are these things?***
- ***Do you help your mom/dad/brother/sister when they are sad or tired? How do you help them?***

Active listening is key. Show empathy and validate the child's emotions so they feel heard and understood. Use paraphrasing to clarify and expand on what they are saying, which helps confirm that you have understood their concerns.

If the child has a general health concern

It is important to identify whether there are underlying factors or unaddressed responsibilities. Explore with them whether there are aspects of their life or family situation that may be causing stress. Ask questions such as: "Are there things in your life that worry you or make you sad?" or "Do you sometimes feel overwhelmed by situations at home or at school?" Identify signs of stress and explore available support resources.

If the child scores moderate to very high on the frequency of tasks

Assess whether these responsibilities are affecting their overall well-being. Ensure they are not experiencing excessive stress or concerns about balancing family responsibilities with their personal needs. Encourage them to balance their responsibilities with their own personal needs, such as time for fun, homework, playing with friends, engaging in sports or hobbies.

Ask open-ended questions such as: "Can you tell me about what you do specifically to help around the house?", "How do you feel about these tasks?" or "What does a typical day look like for you?"

Explore the most challenging aspects by asking: “What aspects do you find most challenging?” or “How do you feel after completing these tasks?”

It is important to remember that YC typically take on responsibilities beyond what is expected for their age. Rather than focusing on a specific number of tasks, make sure the child is not experiencing undue stress from balancing family responsibilities with age-appropriate responsibilities. Help the child understand that they are not expected to take on too much. Also identify available resources by asking questions such as: “Is there anything that could help you feel better?” or “Do you know of any people or groups that could help you?”

If the child is worried about a sick relative but says he or she doesn’t help

You can explore why they say they don’t regularly help their relative despite their concern. This may be due to their perceived role or family factors. Ask questions such as: “What are your main concerns about your relative?” and explore any feelings of helplessness or guilt they may be experiencing. They may also be taking on a caring role without realizing it.

If the child says they are helping a loved one who is sick

Discuss how this might affect them. Ask them how they feel and explore the emotions they experience in this situation. Questions such as: “How do you feel about helping your loved one?” or “What aspects of it seem harder or easier?” can be helpful. Also discuss the support available to them and the person they are helping.

Sometimes, YC may feel positive emotions about their role. For example, they may feel proud to be helping their loved one or feel that they have a stronger relationship with their relative. It is important to acknowledge their involvement and invite them to talk about the positive aspects of their experience. Appreciate their skills while providing information about the support available for the more difficult aspects.

If the child expresses another concern

The child may mention, in the comments space or during the discussion, a situation that he or she is experiencing at school or at home that is not directly related to family care (e.g., bullying, stress related to academic performance, bereavement). If this situation seems worrisome, it is important to inform the parents or guardians. Also suggest relevant resources and concrete actions to support the child in this context.

Important distinctions

- ***Parentification:*** This occurs when a child takes on the role of a parent, which may include household chores or emotional support. This role reversal can affect their development because their own needs may be neglected. Not all YC are parentified, but it is important to recognize this dynamic when it occurs.

- ***Helpfulness:*** Being helpful means offering help in a voluntary and appropriate way. This is generally positive as long as it does not become a burden. Helpfulness should be done in a way that does not cause undue stress for the child. Unlike parentification, it does not necessarily involve taking on parental responsibilities, and not all YC are necessarily overburdened with tasks.

Follow-up and actions

At the end of the discussion, it is important to summarize the key points to check that you have understood the situation and the child's concerns. For example, you might say "Here is what we talked about today. Did I understand correctly?" This allows the child to confirm or clarify what has been shared.

Then plan next steps together by defining concrete actions to meet the needs identified. Suggest solutions by making suggestions such as "Here are some ideas about how we can improve the situation. What do you think?" It is also important to discuss the possibility of talking to someone who can provide additional support if needed.

Offer support by starting with the means identified by the child and then providing resources that are appropriate to the needs expressed. For example, you might say: "I'll help you find resources that might support you" or "We can consider talking to someone who might be able to provide more support. For example, who can help you if you're having a problem or concern?".

Also offer tools and strategies to help the child cope with the challenges they face, such as techniques for setting limits, tips for taking care of their mental and physical health, or methods for expressing their feelings. Encourage their participation in support groups where they can meet other children in similar situations to help them feel less alone and benefit from a supportive environment. If the child shows signs of distress, it is important to provide appropriate psychological support. This may include referral to a mental health professional or arranging intervention sessions with a therapist or organizations that specialize in helping YC.

It is also important to monitor the child for signs of emotional exhaustion or overwhelm. Assess whether the child's caregiving responsibilities are interfering with his or her personal, academic, or social development. If necessary, involve other family members or professionals to help ease the burden.

Finally, ensure regular monitoring to assess how the situation is evolving and to adjust interventions as the child's needs change. This will ensure that the support provided remains relevant and effective.

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Resources for youth

Psychosocial Support

A free, confidential telephone helpline offering professional advice and referral to community resources for psychosocial or mental health problems.
811, ext. 2 → *https://www.quebec.ca/en/health/finding-a-resource/info-social-811*

L'Appui

An organization that provides services for caregivers (including a free telephone support service) and the organizations that support them. → *https://www.lappui.org/en/*

Proche aidance Québec

A group of organizations for caregivers, with a map of resources available in Québec.
→ *https://procheaidance.quebec/organismes-soutien/*

Famille choisie

A support program for caregivers from LGBTQ+ communities.
→ *https://www.fondationemergence.org/famillechoisie*

LaPProche

An online guide to inform and equip young people (12 to 25) who have a parent with a mental health problem. → *https://lapproche.uqo.ca/guide-jeunes-outils/*

Cap Santé-Mentale

An information and resource portal for young people who have a loved one with a mental health problem. → *https://www.capsantementale.ca/portail-jeunes-adultes/*

Ami-Québec

An organization for people who have a loved one with a mental health problem, offering support and training. → *https://amiquebec.org/*

Youth In Mind Foundation

An information and resource initiative to prevent mental distress among young people.
→ *https://fondationjeunesentete.org/en/*

Aire ouverte

Health and wellness services for young people aged 12 to 25, available throughout Québec.
→ *https://www.quebec.ca/en/health/finding-a-resource/aire-ouverte-services-for-young-people-aged-12-to-25*

Kids Help Phone

Online mental health services available 24/7 across Canada.
→ *https://kidshelpphone.ca/*

Tel-Jeunes

Online resources and services for youth, with peer-to-peer sharing and professional intervention.
→ *https://www.teljeunes.com/en*

Appendix A

Risk and protective factors for young carers

Certain characteristics related to the young person, their family, their environment, their culture or their lifestyle, increase the likelihood that they will develop difficulties related to their caregiving role (**risk factors**). Conversely, certain characteristics may reduce the young person's risk of developing difficulties and promote their good mental health (**protective factors**). Here are examples of risk and protective factors (Chikhradze et al., 2017; Janes et al., 2022; Rose et al., 2010):

Risk factors	Protective factors
• Physical health problems • Stressful life events (e.g., financial difficulties) • Family conflict • Low social support • Cultural representations of the caregiving role	• Good physical health • Ability to cope with stressful events (resilience) • Communication and problem-solving skills • Ability to seek help and resources, if needed • Engagement in one or more activities • Family adaptability • High social support • Access to leisure activities

A number of studies report more frequent difficulties among young carers in terms of health (physical and mental) and psychosocial and academic adjustment (e.g., Becker and Becker, 2008; Lacey et al., 2022). Here is a summary of the observed findings:

- Higher levels of anxiety and depressive symptoms
- Higher levels of stress
- Lower perceived well-being and quality of life
- More negative affect (e.g., anger, guilt, sadness, worry)
- More chronic mental health problems
- More frequent risk-taking behaviours
- More frequent suicidal thoughts
- Higher levels of fatigue (physical and emotional)
- More physical ailments or injuries (e.g., migraines, back pain)
- More physiological problems (e.g., insomnia, overweight)
- More school absences and tardiness
- Increased risk of dropping out of school
- More marked difficulty concentrating