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Summary in English:

STUDY OF YOUNG CARERS 2022 – BY THE NORWEGIAN DIRECTORATE OF HEALTH PERFORMED BY OPINION

Following is a summary of the national Norwegian study of young carers 2022.

The purpose of the project has been to gain insight and knowledge about the life of young carers, how they experience their current situation and what needs they might have.

Young carers are defined as people aged 16-25 that are, or have been, carers of parents, siblings, and other close relatives.

METHOD AND SAMPLE

The data was gathered using a two-pronged method, first through a quantitative web-survey and later through qualitative in-depth interviews with a handful of respondents.

A representative sample of young respondents ages 16-25 were pulled from Norstat's population databank. Respondents were then asked three questions meant to filter out respondents who were not care givers.

After the initial questions, 18% of the original sample was left, which resulted in a simple size of $n = 575$ young carers.

Additionally, Opinion conducted 42 in-depth interviews with young carers. The interviews were conducted to gauge young carers attitudes and lived experiences.

Key characteristics of the survey sample:

- There are more females than males in the sample, with 72% of respondents being young women.
- The majority of the sample is made up of young carers over the age of 20.
- About 60% of the respondents are, or have been, carers for siblings or their mother.
- The majority of respondents are students (secondary school/high school, university, or vocational school)

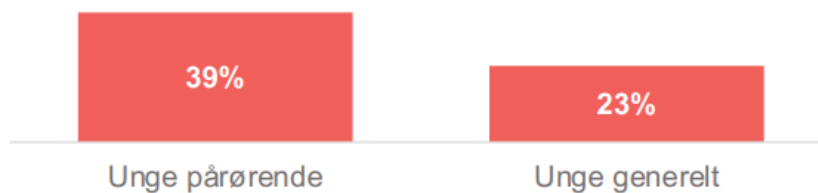
CHARACTERISTICS OF YOUNG CARERS

Most of the respondents are carers for people with mental disorders (33%), followed by severe somatic illnesses (23%) and drug addiction (19%).

6 out of 10 respondents lived with the person they cared for during their upbringing. 2 out of 10 currently resides with the person they care for. Naturally, those under the age of 18 are overrepresented in the latter statistic – with 56% of 18-year-olds reporting that they currently reside with the person they care for.

Almost 40% of young carers in Norway experience worsened mental health. Respondents that care for people with mental disorders state their own mental health as worse than the general sample. Additionally, those that care for mothers also experience their own mental health as worse than those that care for their fathers or siblings. Among young carers 39% characterize their own mental health as poor or very poor, it is almost double that of young people in general when comparing similar data of the general youth population (see figure 1 and 2).

Hvordan opplever du din psykiske helse gjennom de siste 12 månedene? (andel som svarer svært / ganske dårlig)



Alt i alt, hvor fornøyd er du med livet ditt for tiden? (andel som svarer svært / ganske misfornøyd)

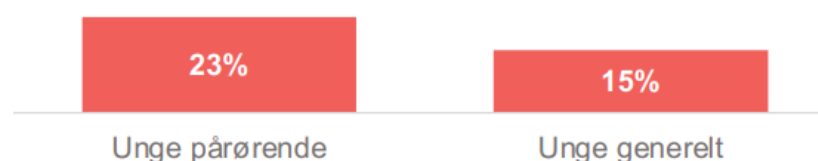


Figure 1 & 2: “how do you experience your own mental health during the last 12 months?” and “all in all, how satisfied are you with your life at the moment?”. Both questions show the percentage of respondents who answered “poor” or “very poor”. The columns are comparisons between young carers (left) and young people in general (right)

CONSEQUENCES OF BEING A YOUNG CARER

The respondents were presented different types of consequences of being close to someone who is sick. The results show that the greatest consequences are social in nature. Over 60% of respondents report that they have decided against bringing friends home (to some extent or to a great extent). Similarly, 44% have decided against going to parties or on holiday with friends. The role of a young carer also affects their schoolwork, with 42% reporting that they do less homework.

Young carers for people with drug addiction stand out as a group that suffer socially to a greater extent than other groups.

When asked if there is something the respondent would like to do that they cannot do because of their situation, around 15% of respondents feel that they cannot move out or study far from home.

HOW YOUNG CARERS CONTRIBUTE

4 out of 10 respondents help the person they care for in their everyday life. Those who care for their mother or siblings contribute more to everyday life (48% and 44 %) than those who care for their father (30%). Naturally, those who reside with they person they care for contribute more than those who do not. Young carers who care for someone with drug addiction contribute far less than other groups.

When asked what the respondents contribute with, the vast majority of young carers report emotional contributions like: cheering up, motivating, engage in conversations, and comfort. Practical contributions are also common with respondents reporting that they: cook, go shopping, and clean. 2 out of 10 respondents also contribute with health-related tasks like helping with medication and taking the patient to doctors appointments.

When asked to if the respondents feel like they contribute to much or not enough:

- 41% reply that they contribute about as much as they like
- 2 in 10 (18%) feel like they contribute too much
- 1 in 4 want to contribute more (figure 3).
- Around half of young carers also report that they have more responsibilities at home than what is common among people their own age (figure 4)

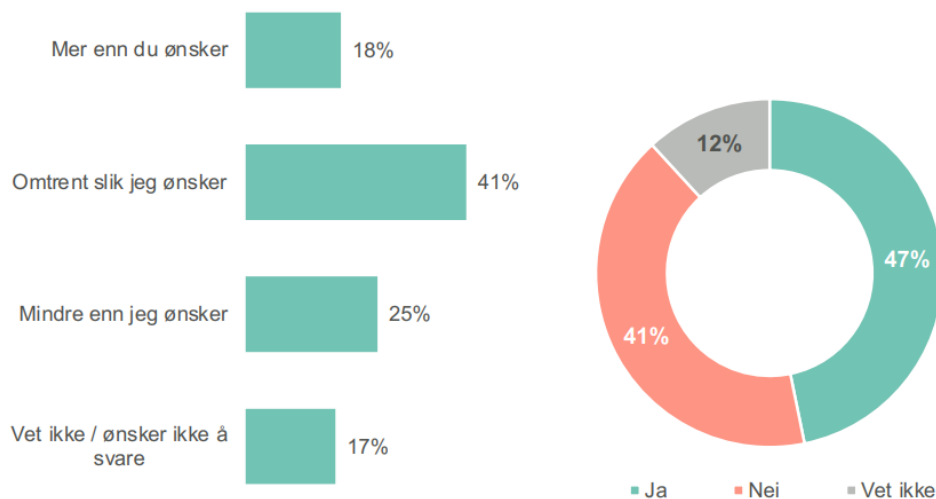


Figure 3 & 4: “Do you experience that you contribute... 1: more than you want, 2: about as much as you want, 3: less than you want, 4: don’t know” and “Do you think you have more responsibilities at home than what is common among people your own age?” (green = yes, red = no)

Respondents that contribute at home also report, to a greater extent, that they experience positive emotions related to their contributions. They feel that their contributions matter and that they feel closer to their family. However, over half of the sample also report that they feel stressed. The results show a compound situation whereby young carers experience both positive and negative consequences from their situation.

WHAT DO YOUNG CARERS WISH FOR?

When asked what type of help the respondents wish for to make everyday life easier, the majority answered:

- proper treatment and care for the person who is sick
- 2 out of 10 also wished for more information about the illness
- more information about being a young carer
- a plan for what to do if the situation becomes more difficult.



IN-DEPTH INTERVIEWS

The in-depth interviews strengthen the results from the survey. Five insights can be taken from the interviews:

1. Young carers experience positive and negative consequences from their situation. They feel increased self-worth but many also report that they feel exhausted and want to move away from their situation.
 - a. A repeating theme is uncertainty. While many young carers display a great degree of adaptability the lack of certainty in their situation can be stressful.
2. Young carers are affected mentally, emotionally, and socially.
3. Young carers want external validation of their role as carer and their contributions. They need an ally (teacher, nurse, or social worker) to validate, legitimize and normalize their emotions and reactions.
4. Young carers want to be included and involved. They feel they can take on greater tasks, however, the responsibility can quickly devolve into a stressful and difficult situation.
5. The help that they are offered needs to be individualized, accessible, and offer continuity over time.

Conclusions:

MOST IMPORTANT FINDINGS FROM THE SURVEY AND THE IN-DEPTH INTERVIEWS

1. Young carers report significantly lower mental health and well-being than the general and comparable population.
2. The greatest consequences of being a young carer is social in nature. Their situation affects their friendships and their schoolwork.
3. Young carers experience increased self-worth and feel that they can handle challenging tasks. However, there is a thin line between the positive consequences and negative ones like exhaustion and anxiety.
4. Young carers want more information about their situation, both in regard to the patient and to their role as a young carer.
5. Young carers need external validation of their emotions and reactions, be it from a health-care professional and/or teachers .

FACTS

The survey is a part of the [Norwegian strategy for informal carers 2020-2025](#) launched December 2020. A part of the strategy is to get national data on carers situation and challenges. So far three different national surveys have been performed under the supervision of the [Norwegian directorate of Health](#):

2020-21	General situation and challenges for informal carers in Norway
2021-2022	Challenges for 4 large groups of informal carers – parents/carers for very sick and/or disabled children/youth, for patients with chronic conditions/diseases, Patients with mental health illness and/or addiction problems and sick and frail elderly
2022-2023	Young carers 16-25 years in Norway – first national survey

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