Patient Related Outcome Measures

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ORIGINAL RESEARCH

“Time to Be Young?” – A Qualitative Study Exploring the Impact of Attending a Course for Young Carers Who Have a Parent with Dementia

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Purpose: Being a young carer of a parent with dementia can be challenging, with many carers undertaking various practical and caring tasks. The weekend course Time to be young? gathers young carers, aiming to support them to cope with their challenges in everyday life. The aim of this study was to explore their role as a caregiver and the experienced impact of the course on their strategies of coping in their everyday life.

Participants and Methods: The study had a qualitative descriptive design inspired by Lindseth and Norberg’s phenomenological hermeneutical method, using individual semi-structured interviews for data collection. The participants were recruited from former participants of the course Time to be young?, and the final sample included eight participants.

Results: Through the analysis, four main themes were identified: 1) Help to accept the situation, 2) A sense of community, 3) The need for information and 4) The need to live one’s own life. The study found that attendance at Time to be young? for young adults having a parent with dementia affected their coping strategies in their situation as a young care.

Conclusion: The study demonstrated the importance of courses like Time to be young?, and need for a meeting place, tailored information about dementia, and an opportunity to share and reflect upon their experiences as a young carer.

Keywords: dementia, young carers, young adults, course, information

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Introduction

Of the 101000 people with dementia in Norway, about 2100 of them are under the age of 65.[1] Most of them live at home. In addition to professional caregivers, their families put in large efforts to care for them both with practical and personal caring tasks.[2] These carers include youths (under 18 years old) and young adults (18–30 years old). It is estimated that 75% of people under the age of 65 in the early stage of dementia have children that are under 30 years old, and 25% have children under 18 years old.[3] The Norwegian government’s action plan on dementia emphasizes that family members of people with dementia must be supported, guided and ensured respite care services.[2]

Having a caregiving role for a family member with dementia is a life-changing event that can lead to emotional strain, social consequences and fear for the future, but it can also be a meaningful role with positive aspects.[4] Being a young carer with a parent with dementia is described as being challenging, with many young carers experiencing a role reversal. They may have to take on a parent-like role towards their own parent,[5–8] as well as taking responsibility for both caring and practical tasks at home.[8,9] Young adults often have limited experience with and knowledge of crisis and disease.[10] When the parent receives a dementia diagnosis, many young carers describe a feeling of shock, a chaos of emotions and thoughts about how the future will look like.[11,12] Having a parent with dementia might bring a constant feeling of loss and grief,[6,13] especially over a lost future with the parent with dementia.[11] Additionally, many young carers have worries

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Table 1 Overview of the Participants

Nr.	Fictive Name	Age at the Time of Interview	Living Condition	Participated with Siblings at the Course
1	Daniela	30	With partner and kids	No
2	Beth	18	With the parents	Yes
3	Lilly	22	In a collective	Yes
4	Nathalie	28	With partner	Yes
5	Emily	25	With partner	No
6	Catherine	23	With the parents	Yes
7	Wilma	34	Alone	Yes
8	Anna	25	With partner and kids	No

Note: Only one participant was male, all the participants are presented as females to ensure anonymity.

about the parent without dementia and how they struggle to accept and deal with the changes brought about by the dementia diagnosis.[7]

Despite the knowledge in the healthcare system about the unique challenges of being a young carer, young carers experience that few available services are tailored to their needs.[6] They seem to receive limited information about the disease[5,6] and receive less support from the healthcare system than expected.[9] They express needs for supportive services that provide them with information about dementia adjusted to both the young onset dementia subtype, the carers' age and their stage in life.[14] Some also mention the need for help in communication with the healthcare system.[9] Young carers promote the usefulness of support groups,[6,15] believing it would be encouraging to talk to others in the same situation as themselves.[5,7–9]

In Norway, a course has been developed to meet the identified needs of young carers. The course *Time to be young?* (Tid til å være ung?) is a nationwide weekend-long course for young adults between the ages of 18 and 30 who have a parent with dementia. The course has run twice a year since 2011 by the Norwegian National Centre for Ageing and Health in cooperation with the Norwegian Health Association as well as healthcare staff from several hospitals and municipalities. From 2012, the courses have been financed from the Norwegian Directorate of Health through the National Dementia plan.[16] The course is led by professional staff and peers of young carers. The main aim of the course is to gather young carers and provide them with support to cope with their challenges in everyday life.[17] It's a residential course held in person, and it is a maximum of 16 participants per course. The course is held from lunch Friday to lunch Sunday and consists of information about dementia and other relevant themes such as healthcare, laws and rights, services, and significant strategies of coping in everyday life as a young carer. Additionally, support groups and socialisation with the other participants such as board games and team-building activities are facilitated.[16] Evaluations of the course using surveys on the last day of the course reveal that the participants find the course profitable and emphasize the importance of openness, social interaction and being with other young adults in the same situation[16] In the study of Johannessen et al courses specifically designed for young carers were described as an important factor positively influencing their resilience.[18] However, when searching for previous research on the topic, we have found limited studies on the impact and experiences of courses and information interventions adjusted to the needs of young adults having a parent with dementia.

The aim of the current study was to explore the experienced impact of the course *Time to be young?* on the participants' strategies of coping in everyday life in their role as a young adult with a parent with dementia.

Materials and Methods

The study had a qualitative descriptive design inspired by Lindseth and Norberg's phenomenological hermeneutical method.[19] Individual semi-structured interviews were used to collect the data, aiming for a deeper understanding of the participants' experiences of the course and its impact on their everyday lives.

Recruitment and Sample

The participants were recruited from former participants at the course *Time to be young?* run in the period from 2016 to 2019. A total of 86 former participants were contacted by Email in January 2020 with information about the project and an invitation to participate. Reminders were not sent. There was no deadline for the invitation to participate in the study. But when the interviews were conducted, three months after the invitations were sent, we stopped recruitment. Nine of the 86 accepted the invitation. One withdrew; hence, the final sample included eight participants. An overview of the participants are presented in Table 1.

Interviews

In line with the phenomenological hermeneutical method, the interviews were conducted with the intention to collect the participants' experiences and stories.[19] The interviews' aim was to explore topics around the participants' life situation as young carers, how they experienced the course and how their lives were influenced by the course after participation. Focusing on the following main themes: Why did you participate in the course? How did you experience the participation at the course? What were the most important parts of the course for you? How has the course affected your everyday life? Did your coping strategies change after the course? It was considered important to conduct the interviews in a safe setting. Although it was important to encourage the participants to freely describe their experiences, a certain structure in the interviews was needed to ensure that some mutual aspects on each theme were illuminated. Based on the aim of the study, a semi-structured interview guide was developed.

All the interviews were conducted by the first author C H-J. They were conducted on a digital platform, FaceTime or Skype, and recorded. The interviews lasted between 37 and 78 minutes and were conducted between March 1st and April 1st, 2020.

Analysis

The interviews were transcribed verbatim and analysed thematically inspired by Lindseth and Nordberg's phenomenological hermeneutic model[19] following three steps: 1) naïve reading, 2) structural analysis and 3) comprehensive understanding. In the first step, the interviews were read several times and formulated as a short text, representing the first understandings of the texts. In the structural analysis (illustrated in Table 2), meaning units in the text were identified and reformulated into condensed meaning units, subthemes, themes, and main themes. These themes were validated against the naïve understanding and vice versa. In the comprehensive understanding step, the formulated themes were summarized and reflected in relation to the aim of the study and already existing literature and research. In this step, the interviews were read again, this time with the validated themes and naïve understanding in mind. The naïve reading and the initial coding of data were made by the first author (C H-J) and the co-authors (IH and AMMR) took part in the structural analysis and the comprehensive understanding (steps 2 and 3).

Table 2 Example of the Structural Analysis

Meaning Unit	Condensed Meaning Unit	Sub-theme	Theme	Main Theme
And to, in a way, know that there are others that are in the same situation. It makes you feel less alone in it all. And that also makes you accept it a bit more, I think. That there are several others in the same boat.	Meeting others in the same situation as myself helped me to accept the situation a bit more.	Meeting others helped me accept my situation as a young carer	Accept the role as a young carer	Help to accept the situation

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Table 3 Overview of Main Themes and Sub-Themes

Help to Accept the Situation	**A Sense of Community**	**The Need for Information**	**The Need to Live One's Own Life**
To accept the disease	The importance of meeting others in the same situation	To not get sufficient of information after the dementia diagnosis	The role as a young carer
The course gave a perspective on their own situation	To stand alone in the situation	The course became a source of information	Life consists of several roles
Accept the role as a young carer	To participate at the course with siblings		The course relieved on their guilt
	The experience of fellowship with the other participants was not only linked to the course weekend		

Ethical Considerations

The study complies with the Declaration of Helsinki. The study was not classified as medical and health research according to regulations in Norway and thus, the regional ethics committee was not involved in the approval process. Studies like this need approval from a national data protection authority and were approved by the *Norwegian Centre for Research Data* (NSD) (reference number: 946383). All participants gave their written informed consent to take part in the interviews and the publication of their anonymized responses and direct quotes. They were informed that the participation was voluntary and that they could withdraw their consent without consequences whenever they wanted. Only one participant was male, so all the participants are presented as females to ensure anonymity.

Preunderstanding

The first author, C H-J, is a nurse working with information regarding family carers of people with dementia, including arranging courses for children and young adults with parents with dementia. She also has personal experience in this realm, as she had a father with dementia when she was young.

AMMR is a nurse with clinical experience supporting people with dementia and their families and involvement in research projects concerning people with dementia.

IH has a background in psychology and a PhD on the topic of dementia and user participation.

Results

Through the analysis, four main themes were identified: 1) Help to accept the situation, 2) A sense of community, 3) The need for information and 4) The need to live one's own life. The main themes and sub-themes are listed in Table 3.

Help to Accept the Situation

The participants described that it was hard to accept that their parents were diagnosed with dementia and the changes it entailed. *I have not accepted it yet, really (...) It's hard to accept that I am losing dad, and the future we will not get together (Daniela)*. Their participation in *Time to be young?*, where they received more information about dementia and met others in the same situation as themselves, was described as helpful in the process of accepting their reality. *It really helped (...) Okay, it is what it is... It sucks and it is not supposed to be like this, but others have overcome the same. Then I will also make it (Lilly).*

Several participants described that the information they received about dementia at the course helped them to understand more about their parent's situation and how they as carers could contribute. *If you do not know how a disease affect someone, is it hard to understand why a person react the way they do (Natalie)*. Through sharing experiences and thoughts with the other participants, they became more aware of their own situation and the resources available to them.

A Sense of Community

To meet others in the same situation was important for the participants. Many of them told that this was the reason for attending the course. *I think that sharing experiences and meeting others gave me the most benefit (Anna)*. Sharing their experiences with others made them feel like they were not the only ones in the world to feel the way they did. *(...) Someone in the same situation that could understand my frustration and my thoughts. Because none of my friends does that (Beth)*. These common experiences lead to a sense of community. Many of the participants described an experience of being lonely in their role as a young carer, either because they had a limited network, or because no one in their network was able to help them. Several described that they considered the other participants from the course as friends, and that they stayed in touch with each another after the course.

Some of the participants attended *Time to be young?* together with their siblings. These participants described how the course helped them to accept that they dealt with their parent's disease in different ways to their siblings. Furthermore, participating with siblings became a new arena for conversations and gave them a deeper understanding and acceptance of each other's feelings and experiences. *I think it was very good for us to get an understanding of how the other (sibling) experienced the situation. .... that is not something we would have sat down to talk about on our own, most likely (Nathalie).*

The Need for Information

Participants said that they had insufficient knowledge about dementia, what the disease entails and what to expect of the future in advance of the course. Many unanswered questions about dementia lead to uncertainty and strain. Participants described taking actions to get the information they needed on their own – often through the internet. For some of them the need for information was one of the reasons for attending the course. *And we were very ready to get information and to learn more because we had many questions that we felt that we did not get the answers to, and we did not have anyone to talk to at that point (Wilma).*

The course became a source of information about dementia, relevant services and how to cope with the situation. However, even though the information was long awaited, it could also be overwhelming, and some participants felt it was burdensome to receive so many details about the progress of the disease and its severity. Those that attended the course with their siblings explained the value of receiving the same information. *The biggest benefit was actually the fact that me and my sister got the same knowledge (Catherine).*

The Need to Live One's Own Life

The participants described that they contributed with both caring tasks and practical responsibilities in caring for their parent with dementia. Some had sole responsibility for their parent with dementia, while others took on partial responsibility to help their other parent. *And now when my father has gotten worse, my mother requires more of me also (Beth). When I am at home, I ... take responsibility to relieve my mother a bit (Lilly)*. This role was described as burdensome. To be able to cope with the situation, several described the need to sometimes withdraw from their role as a carer. *It varies, how often I am at home, because sometimes I need to withdraw myself. Because it is too much (Wilma)*. Social support was emphasized as important for them to be able to live their own lives.

Several of the participants thematized that they wished to live more "normal" lives as young adults and discussed how the course taught them the importance of finding time in their lives to just be themselves: *So, now the course is called* "Time to be young?", *and that was actually not so dumb (Daniela). It changed our situation totally. Both me and my sister agrees that it is* 'before and after' *Time to be young? (Nathalie)*. The participants stated that the course helped them to relieve themselves from their guilt. They noted that the staff at the course supported them, reassuring that prioritizing their own lives was important: *It was like SO good to have some grown-ups there who just ... ensured us that we do ... things right, and that we do the best we can, And that meant a lot for my every day. I have a lot less guilt and much less stress (Anna).*

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Discussion

The aim of this study was to explore the participants' experiences of the course *Time to be young?* and what impact the course had on their strategies of coping of everyday life and in their role as a caregiver.

The results showed that the participants found the course useful. It gave them much needed information about dementia and how their parent was expected to change as well as tools to better deal with their situation. Meeting and getting to know peers gave them a sense of community. The discussion will further address these results to get an extended insight into how the participation affected the young carers.

Getting a Bigger Understanding

One of the main findings of this study is how little information some of the participants had received about dementia before the course and the importance of the course in that sense. A recent Norwegian study revealed a common experience among family carers – that good quality information about the diagnosis and the healthcare system is one of the most valued sources of support in their situation.[20] In Norway, healthcare personnel are obligated to give all caregivers general guidance and information about the diagnosis[21] Still, studies show that young carers receive insufficient information about their parent's dementia.[5,6] The opportunity to get more information relevant to their situation was expressed as one of the participants' main reasons to attend *Time to be young?*. Having a lot of questions and not knowing where to get the answers, is undoubtedly a stressful situation. It is reason to believe that increased knowledge about dementia will ease the strain of young carers. Additionally, knowing what to expect in their situation likely makes it easier to accept and cope with the challenges associated with it.

Previous studies on young carers have revealed that searching online for information about dementia is a common consequence of not receiving necessary information elsewhere.[7] These findings were confirmed by the participants in the current study. A great amount of information of various quality is available about dementia online. There are reputable online tools that offer accurate information about dementia, but finding these sources of information requires knowledge about where to look and the ability to critically judge which sources to trust. When the participants attended *Time to be young?*, they received relevant information about dementia from healthcare personnel, explained in a way that they were able to understand. Having access to this kind of accurate information appropriate for their situation could likely reduce the amount of confusion they experience in their role as a caregiver.

Furthermore, the course was described as useful in learning strategies of how to cope with one's situation. As most young people have limited experiences with crisis and disease, the consequences of being a young carer can be huge.[10] Studies emphasize that young carers do not only need information about their parents' dementia but also need to know how to cope with the situation.[5] In the course *Time to be young?*, the topic "how to cope as a young carer" is an ongoing theme. They describe feelings and thoughts that can be normal for young carers and give information about various measures that may be useful for both the parent with dementia and themselves as young carers. The information provided, together with sharing experiences with others in the same situation, might lead to a greater understanding and awareness of resources and coping strategies. The carers' ability to cope is of great importance in how they handle their role. An "active" coping style will reduce the feeling of burden,[22] along with employing strategies to try to change and influence factors that lead to stress. Examples of active strategies are to find different caregiving solutions or to obtain more information about the situation. This can result in reduced demands, challenges, and stress.[23] The participants described that their actions, thoughts, or decisions had changed after attending the course. As a result of the course, they use significant strategies and make more active choices to cope with their situation and, hence, experience less burden. This will hopefully continue to influence their sense of self and responsibility throughout their parent's course of illness.

The Need to Be Understood

Meeting others in the same situation as themselves seemed to fill a void in the participants' lives. Having a parent with dementia when being a young adult is a situation not many people experience. Consequently, young carers seldom meet others they can relate to. In Norway, most municipalities offer support groups for family carers of people with dementia.[1] Previous research has found that young carers emphasize support groups as a useful platform.[6,15] Still, some have experienced that participation in groups with a wide spectre of carers both in age and relation to the person with dementia is challenging as other participants often have very different experiences.[5] A young carer between the age of 18 and 30 usually has little in common with elderly spouses or partners of people with dementia. Many of the participants in this study described that they had no one to talk to that really understood them. Young carers have the need to talk with someone, but preferably want to talk to someone in a similar situation to whom they can relate.[5,7]

Previous research has found that young carers receive less support from the healthcare system than they expect[9] and that they have few available services tailored to their needs.[6,24] Additionally, they are often barely involved and poorly recognized in the caregiving process by the healthcare personnel.[5] This might lead to some young carers not getting the support they need in their everyday life. In this study, several participants described not receiving the support and information they could have needed. Furthermore, previous studies have revealed that young carers who experience a lack of support from healthcare professionals can feel as if they are not being taken seriously or that the personnel are inconsiderate.[25] As young carers are few compared to older caregivers, healthcare personnel may lack experiences with supporting them and giving tailored information. In many cases, young carers are not considered the closest relative to the person with dementia; thus, the consequence can be that healthcare personnel do not prioritize their time to support both the dementia patient's spouse and the children. The participants in this study expressed the importance of receiving support from the course staff, who acknowledged their actions and efforts as carers. Healthcare personnel who confirm that the young carers' feelings are valid will influence their acceptance and therefore also their coping of the situation.

Strengths and Weaknesses of the Study

A strength of this study was conducting in-depth interviews, which allowed for a deeper understanding of the participants' situations. On the other hand, there are limitations with the data being collected from only eight interviews. Even though the participants were of various ages and life situations, there are still many individual variations of young carers that have not been covered in this study. Hence, the results need to be interpreted with this in mind. Nevertheless, the study gives insight into the experiences and feelings of young carers, and in what way a course can help them to deal with the struggles of everyday life with a parent with dementia.

Conclusion

We found that the young carers' attendance at *Time to be young?* Could affect their experience of coping with challenges in everyday life in different ways. The study implicates that the healthcare system needs more knowledge about young carers of people with dementia and how to support them. It also implicates the need for healthcare personnel who recognize and give support to young carers. The study demonstrates the need for a meeting place, tailored information and an opportunity to share and reflect upon experiences as a young carer of a parent with dementia as well as the importance of courses like *Time to be young?*. To tailor support and services to young carers, more information about how healthcare services support and follow up with this group is needed and should be the objective of future research.

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Disclosure

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