

Research Article

Insights from Health and Social Care Professionals Supporting Children and Young Adults with a Parent Diagnosed with Dementia: An Interview Study

Marie Tyrrell ^{1,2}, Andreas Jönsson,¹ Ulrika Södergren,¹ Ragnhild Hedman ¹,
Jonas Sandberg ¹ and Åsa Gransjön Craftman ³

¹Department of Nursing, Sophiahemmet University, Stockholm SE-114 86, Sweden

²NVS, Division of Clinical Geriatrics, Karolinska Institutet, Stockholm SE-114 86, Sweden

³NVS, Division of Nursing, Karolinska Institutet, Stockholm SE-141 52, Sweden

Correspondence should be addressed to Åsa Gransjön Craftman; asa.craftman@ki.se

Received 5 July 2023; Revised 2 April 2024; Accepted 8 April 2024; Published 24 April 2024

Academic Editor: Helen Skouteris

Copyright © 2024 Marie Tyrrell et al. This is an open access article distributed under the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

Dementia is recognised as one of the major global health and social care challenges of present times. When the onset of dementia occurs in midlife, there is an increased possibility that there are children and young adults involved who are dependent on the parent concerned. The aim of the study was to describe health and social care professionals' experiences of identifying and supporting children and young adults with a parent with dementia. A qualitative descriptive approach was carried out with individual interviews of health and social care professionals, using a semistructured interview guide. Thirteen participants in rural and urban areas in Sweden were interviewed. The overarching theme, advocating a forgotten group with three categories were identified. They combine and reflect health and social care professionals' experiences of identifying and supporting children and young adults with a parent with dementia. Health and social care professionals who encountered children and young adults with a parent with dementia described how they were not sufficiently trained in supporting this group and identified a general shortage of available appropriate support services. The children and young adults were also described as a forgotten and overlooked group in need of affirmation and support in a more systematic way.

1. Introduction

Dementia is recognised as one of the major global health and social care challenges of present times [1]. Dementia can entail significant consequences for the health, well-being, and life course not only for the person with the diagnosis but also their family [2]. There is a tendency in society to equate dementia with aging and older people [3]. While aging is the biggest risk factor, persons under the age of 65 years are also at risk of developing dementia. The worldwide prevalence of younger onset dementia (YOD) has been estimated to be 119 per 100,000 population corresponding to 3.9 million people [4]. Alzheimer's disease is the most prevalent cause of YOD, representing 15 to 40% of the people diagnosed. Other causes of YOD are, for example, frontotemporal dementia,

Huntington's disease, Lewy body dementia, and vascular dementia [5]. The majority of persons with dementia in Sweden (72%) reside in the community with persons with YOD less likely to receive support from home care services than their older peers [6].

As the onset of symptoms of YOD often occurs in midlife, the person with dementia may also be a parent to children and young adults who are dependent on them. In these situations, the children and young adults often become key players in the provision of care. In Sweden, it has been estimated that approximately one in every five Swedish adults over 18 provide care for a dependent family member in their own homes and that 12% of these informal caregivers are aged between 18 and 29 years (National Board of Health and Welfare [7]). In a survey in Sweden of 2,424

secondary school students aged between 15 and 16 years, 7% reported that they provided substantial family caring, and 3% reported that they missed out from school at least once a week to care for a family member [8]. This is in line with other research, showing that the percentage of children providing care to a dependent family member in industrialized countries is generally estimated to be between 2 and 8% [9].

In the literature, terms such as: “young carers” and “young adult carers” are frequently used to describe children and young people who are supporting a family member with severe illness (e.g., [9]). However, not all family members of people with severe illness identify themselves as carers. For this reason, we have chosen to use the term “children and young adults with a parent with dementia,” regardless of the terminology used in referred sources. In this study, the children we refer are aged under 18 years, and young adults are aged between 18 and 24 years (although some of the literature refers to slightly different age spans).

Previous studies investigating children’s and young adults’ experiences of having a parent with dementia have shown that the family situation had a significant and enduring impact on their lives (e.g., [10]). More recent research has highlighted the experiences and needs of the children and young adults [11–15]. Prior to receiving a dementia diagnosis, family life was overshadowed by lengthy periods of uncertainty and distress, which impacted the children and young adults negatively [13, 14]. Roles in the family changed, with the children and young adults taking on a more supportive role while receiving less support from their parents (e.g., [13]). The children and young adults struggled to balance their own needs along with the needs of their families (e.g., [15]), worried about the future [14], and experienced stigma [11].

There is a need for improved support for the children and young adults [14] and to see the family as a unit [13]. Support needs identified concerned practical matters such as finding strategies to manage their situation and accessing professional care for their parent. There was also a need for financial support and emotional support from health and social care professionals and from peers with similar experiences [14, 16]. Access to support from professionals who have knowledge of YOD has been described as pivotal by the children and young adults concerned [17]. For various reasons, children and young adults are sometimes reluctant to reveal their situation to others and seek support. This can be interpreted as a means of protecting their parent or themselves from social exclusion, or fear of being separated from their parent. Learning about YOD and about their rights as caregivers was described as empowering [17].

Although children’s and young adults’ experiences and needs when they have a parent with dementia have been extensively described [11–15], health and social care professionals’ knowledge about and experiences of supporting this group has received little attention. A web survey among Canadian nurses (licensed practical nurses, registered nurses, and specialist nurses) identified a knowledge gap in relation to identifying children and young adults who have parents with dementia and how to support them [18].

Previous studies exist describing professionals’ experiences of supporting children and young adults with family members who have various types of mental or physical conditions. For example, Leu and colleagues [19] who interviewed physicians, nurses, and social workers identified a lack of awareness of the situation for children and young adults living with parents with severe illness. The findings suggested that checklists, screening tools, and age-adapted written information could be helpful to raise awareness, identify children and young adults, and provide appropriate support. Further, they considered peer support as potentially beneficial for the children and young adults. The professionals reported a lack of support for this specific group and suggested that interprofessional networks and backup would enable professionals to better support children and young adults with a parent with severe illness. In a web study carried out by the same research group [20], less than one half of professionals in education, health and social care were familiar with the term young carers (or similar terminology). Social care professionals were most likely to offer support. Counselling was the most common type of support followed by peer support and emotional support.

The WHO [21] states that when young adults lack parental guidance and support where they live, learn, and grow, it can undermine their physical, psychosocial, and emotional development. Chirico et al. [13] emphasise the significance of children and young adults accessing professionals with expertise in dementia care and the accessibility of resources. The absence of such facilities acted as a barrier in communication and receiving support for the children and young adults. This study is carried out in Sweden and according to Swedish Agency for Health Technology Assessment and Assessment of Social Services [22], a lack of knowledge exists in how to successfully support young family members to persons with dementia. Furthermore, little is known about how health and social care professionals experience their role in identifying and supporting children and young adults with a parent diagnosed with dementia.

2. Aim

The aim of the study was to describe health and social care professionals’ experiences of identifying and supporting children and young adults with a parent with dementia.

3. Materials and Methods

This study adopted a qualitative descriptive approach [23]. In this interview study, the authors aimed to capture the experiences of health and social care professionals of identifying and supporting children and young adults with a parent with dementia. Employing a qualitative inquiry facilitates participants to describe and create meanings of their distinctive experiences; this in turn leads to the development of knowledge in relation to a phenomenon in question. This approach enables researchers to delve into the nuances of how participants perceive and navigate various

aspects of life, thereby uncovering both intended and unintended outcomes, and shedding light on complex human phenomena [23].

3.1. Study Context. According to the Social Services Act in Sweden [24], local authorities (municipalities) are obliged to provide support for family caregivers. The support is commonly delivered by family caregiver advisers and “dementia nurses,” with a background in social work and/or nursing. The Social Services Act [24] does not specifically mention children and young adults as caregivers; however, it is stated that the social services are responsible for securing safe and nurturing living conditions for children and young adults. Support to family caregivers of people with dementia is also provided by health care professionals and hospital social workers in primary health care and cognitive specialist units, under the regulation of the Health Care Act [25], which states that children’s needs of information and support should be met when a parent is physically or mentally ill or upon the parent’s sudden death. Children’s rights are also stated in the Swedish implementation of the United Nations’ Convention on the Rights of the Child [26]. According to the Swedish National Board of Health and Welfare [27], efforts should be made to ensure that children and young adults are relieved of caring responsibilities that are not regarded as reasonable in relation to their age and maturity.

3.2. Participants. Participants were recruited using purposeful sampling [23] including persons who in their professional role encountered and supported children and young adults with a parent with dementia. All participants were initially invited via e-mails through patient organisations, cognitive assessment clinics, and municipalities. A total of 13 participants were included and completed the study, 12 of whom were women. Eight participants were employed as family caregiver advisers or dementia nurses by municipalities, three were hospital social workers in cognitive assessment units, one was a dementia nurse, and one was a registered nurse in a cognitive assessment unit. They were employed and worked in various parts of Sweden, both rural and urban areas. Four participants had experience of working at summer camps for children and young adults who had a family member with dementia. Educational backgrounds varied among participants; five participants were educated as social workers, another five were registered nurses, and three participants were enrolled nurses. Most participants had further education in care and support of persons and families living with cognitive impairment, with up to 30 years of experience in present employment (median 5 years). The participants’ characteristics are summarized in Table 1.

3.3. Data Collection. Semistructured interviews were conducted by five of the authors (AJ, JS, RH, US, and ÅC), who have previous experiences of interviewing and carrying out qualitative research. The interviews were performed via Zoom ($n = 12$) and via telephone ($n = 1$) in line with the

preferences of the participants. During the interviews, participants were asked about their experiences and strategies of supporting children and young adults (maximum 24 years of age), and resources available to support young caregivers. All interviews were audio-recorded, upon consent of participants, and transcribed verbatim by the authors. The length of the interviews varied between 29 and 84 minutes (median 64).

3.4. Data Analysis. Qualitative content analysis, inspired by Graneheim and Lundman [28] was used to analyse the data. Initially, the transcribed interviews were read through to get a sense of the whole. Meaning units were then extracted, condensed, and grouped into subcategories and categories. A manifest approach was used in identifying meaning units, condensing them and creating subcategories, and categories adhering closely to the literal meaning of the text. Thereafter, a latent approach was used to create the final overriding theme, all in keeping with recommendations from Graneheim and Lundman [28]. Three of the researchers (MT, AJ, and US) conducted the analysis and all authors were involved in the construction of the categories and overriding theme.

3.5. Ethical Considerations. Ethical considerations stated in the Declaration of Helsinki guided the authors in this study [29]. All participants received verbal and written information about the study, explaining the voluntary nature and confidentiality of participation, that they could withdraw their participation at any time and that the data would be handled with confidentiality. This study was conducted in accordance with the International Committee of Medical Journal Editors [30]. Written consent was obtained before the interview started. The study was approved by the Swedish Ethical Review Authority (Dnr 2021-05422-01).

4. Results and Discussion

4.1. Advocating a Forgotten Group. The overarching theme *Advocating a forgotten group* represents how health and social care professionals championed the needs and rights of children and young adults (with family members with dementia) who were not always visible. An overview of the findings is presented in Table 2.

4.2. Engaging with an Overlooked Group. The category *Engaging with an overlooked group* describes health and social care professionals’ efforts to discover the children and young adults and identify their needs. There were also ambitions and aspirations to give voice to what was regarded as an unheard group. The following subcategories were identified; *Locating children and young adults and assessing needs*, *Working beyond the scope of employment*, and *Striving for voices to be heard*.

4.2.1. Locating Children and Young Adults and Assessing Needs. Children and young adults were described as not actively seeking contact with health and social care services.

TABLE 1: Participants' characteristics.

	Sex	Employment	Education	Employer	Experience in care of people with dementia (years)	Experience in present work role (years)
1	Female	Dementia nurse	Registered nurse	Municipality	20	20
2	Female	Dementia nurse	Registered nurse	Municipality	38	38
3	Male	Family caregiver adviser	Enrolled nurse	Municipality	15	1
4	Female	Family caregiver adviser	Social worker	Municipality	31	31
5	Female	Dementia nurse	Specialist nurse	Region	39	17
6	Female	Family caregiver adviser	Enrolled nurse	Municipality	20	4
7	Female	Family caregiver adviser	Social worker	Municipality	13	10
8	Female	Dementia nurse	Registered nurse	Cognitive assessment unit	40	20
9	Female	Hospital social worker	Social worker	Cognitive assessment unit	7	5
10	Female	Dementia nurse	District nurse	Municipality	41	39
11	Female	Hospital social worker	Hospital social worker	Cognitive assessment unit	31	27
12	Female	Hospital social worker	Social worker	Cognitive assessment unit	30	30
13	Female	Family caregiver adviser	Enrolled nurse	Municipality	22	22

Participants felt obliged to find and support these children and young adults. It was not always clear if young children and young adults were involved when a person was under assessment or when they received a diagnosis. The children and young adults were described as often neglected and isolated. A lack of communication and cooperation between health and social care providers was described as aggravating creating barriers to identify and subsequently offer support. The planning of care and support for the person diagnosed with dementia lacked a family perspective. Participants described how some parents wanted to protect their children or young adult by avoiding contact or assistance outside the family. Due to the perceived stigma of the condition, several participants also argued that parents tried to shield the children and young adults from the reality of the situation by excluding them from visits to health care professionals.

“There is such a stigma about the disease. I think that the parent who receives a diagnosis, even if they have a healthy spouse, are trying to protect the children by excluding them. This is completely wrong as the children are so incredibly involved back home” (P.5)

Participants also pointed out difficulties in convincing other professionals and policy makers of the children's and young adults' vulnerability. These difficulties were partly due to the condition being regarded as a disease seen in old age and that the parent diagnosed with YOD did not appear unwell and could carry out daily activities.

4.2.2. Working beyond the Scope of Employment. Participants described how they worked beyond their scope of employment in supporting children and young adults as opposed to adults. It was formally within the scope of their job description to support adults. Participants experienced a lack of guidance in managing situations involving children and young adults.

“Eh. . . but then, of course. . . you must have turned 18. So, if you're younger than that, then. . . there's not much help available!” (P.1)

Participants described an uncertainty about meeting children and young adults, with regard to lack of training, mandate, and/or competence to provide support to children and young adults. Some stated the importance of working closely with a colleague in these specific situations. Other participants felt that they were working alone, lacking input and collaboration with colleagues and team members. Participants who were actively engaged in arranging summer camps for children and young adults living with a parent with dementia were satisfied with the support and service they offered. Although not always formally part of the scope of employment, participants described a commitment and sense of responsibility towards the children and young adults. It was important to show the children and young adults that support was close at hand, and not to let go.

“. . . Who will take care of these children? It's not actually me who's supposed to do so, but there's no one else so . . . I've taken every case. . . but there are no routines, etc. like who's supposed to do what. It's like this if a case comes up . . . it usually ends up being me anyway. . . it's not that great actually.” (P.1)

4.2.3. Striving for Voices to be Heard. Participants highlighted the need for children and young adults to talk about their situation although they often did seek support or take initiative for such conversations themselves. Children and young adults were described as a group of unheard voices, for whom the participants were advocating and striving to make heard.

It was important to have knowledge of the help-seeking behaviour of children and young adults. Many children and young adults were described as withholding information about their parent with dementia from their friends and

TABLE 2: Overview of the findings.

Subcategories	Categories	Theme
(i) Locating children and young adults and assessing needs	Engaging with an overlooked group	Advocating a forgotten group
(ii) Working beyond the scope of employment		
(iii) Striving for voices to be heard	Understanding the complexities of the situation	Advocating a forgotten group
(i) Acknowledging a desire to fit in		
(ii) Recognising diversity of needs		
(iii) Tailoring support to meet needs	Building trust and relationships	Advocating a forgotten group
(i) Having a flexible approach		
(ii) Being competent and having confidence		
(iii) Creating a safe environment	Building trust and relationships	Advocating a forgotten group

others in their surroundings. Participants had also experience of meeting children and young adults who expressed severe anxiety, panic attacks, eating disorders, or self-harm behaviour. It was described that children and young adults had a profound need for, and were comforted by, talking to others in similar situations, both in group sessions on social media and at the summer camps. Meeting peers in similar situations empowered the children and young adults to talk about their situation.

“So, when we meet at these (summer) camps . . . you get the feeling that finally there is someone here who understands how it is. . . as neither the school nurse or others do” (P.2)

Participants stated that they had worked actively to promote contact between the children and young adults with policymakers and decision-makers. These meetings endorsed the voices of children and young adults about their situations and were deemed more likely to impact change than the efforts made by the professionals in their roles.

4.3. Understanding the Complexities of the Situation. The importance of understanding complexities of the family situation was highlighted when meeting and tailoring support for the children and young adults. This was described as a multifaceted and challenging task, dealing with both emotional and practical needs. The children’s/young adults’ everyday lives were impacted on many levels by their family situation. The following subcategories are included; *Acknowledging a desire to fit in*, *Recognising the diversity of needs*, and *Tailoring support to meet needs*.

4.3.1. Acknowledging a Desire to Fit in. Participants highlighted the children’s and young adults’ desire to fit in and not deviate from their peers both in terms of the home situation and in school. Prerequisites of normality were described in both social and practical contexts and included financial stability.

Children and young adults often felt obliged to take responsibility in the home for their siblings’ and parents’ well-being and needs. Participants often described an absence of an adult in the home who could provide help with homework, and finance food, new shoes, or a haircut and recreational activities. This assistance was regarded as essential for the child/young adult to manage everyday life without feeling stigmatized. Many participants highlighted the needs and desires of the children and young adults to be like their peers and have their school as a safe place. For some children and young adults, the school offered support through the school nurse or counsellor. However, not all schools were aligned in their responsibilities claiming that they were not responsible for the pupil’s home situation. In some cases, children and young adults who were referred to the school counsellor for support did not approach the service due to a possible fear of stigmatization.

“ . . . there are those who don’t want to go to the school counsellor as it would be noticed by school friends if they

had a meeting with them, it can be a bit sensitive for children in certain age groups. They don’t want to stick out. . . sometimes the children have assumptions that the school counsellors are a bit odd. . .” (P.11)

In some situations when participants guided the children and young adults to existing support, it was not always acted upon as the support offered did not meet actual needs.

Participants explained that they needed to be mindful of the need to fit in when guiding the children and young adults to forums where they could seek help outside of school time. The youth guidance centre was described as an accepted place to seek help. The importance of meeting others in a similar situation was described and could be achieved through support groups, closed groups on social media, or summer camps designed for children and young adults. Family caregiver advisors acknowledged a need for the children and young adults to know that they were not alone and that there were others of their own age in similar situations.

“I think that the needs I need to meet are . . . if not fully but partly meet. . . and they may not always be aware of the fact . . . they need to understand that they are not alone in this situation. That there are people their age who have the same thoughts, feelings and practical concerns with loved ones as they do.” (P.3)

4.3.2. Recognising Diversity of Needs. Inconsistencies regarding whether the parent’s dementia diagnosis played a role in relation to the children’s and young adults’ needs existed. Differences in needs were identified according to the age of the child and young adult, if concerns about genetic components of dementia were present and concerns about their own health (present and future), and for family planning. Diversity of needs also entailed the diagnosis itself and how it impacted the daily life of the family. These needs varied depending on the parent’s symptom, e.g., if the parent did not recognise them, if they carried out heavy household chores, or if the parent had behavioural symptoms. Based on the parent’s symptoms, the participants stressed the importance for the children and young adults to find individual strategies to deal with their situation. In addition, participants had to reassure the children and young adults that they were entitled to help regardless of the parent’s diagnosis or needs.

It also emerged that children and young adults expressed concerns regarding the possibility that the healthy parent could become ill. Consequently, participants described how the children and young adults could clearly express a loyalty to both parents which in turn could impact on their own well-being. They tended to do everything possible to support the healthy parent, with knowledge that the other parent would die.

“Many times these children . . . want to protect their “healthy” parent, like when they talk about their parent (with dementia) about what they did like Dad did this or that, then the other parent could get upset and cry or the 6

Health & Social Care in the Community opposite . . . Instead of sharing they tend to internalise things. It is when they speak of these experiences we can act and provide support.” (P.5)

Practical needs were also described, such as financial or informational needs about the parent’s condition. Children and young adults were described as having various degrees of knowledge not always being aware if their parents had a diagnosis, and if so, what the diagnosis meant. Participants also described how the children and young adults had a diversity of beliefs and convictions. Some believed that the condition would soon pass by itself compared to those who searched the Internet finding dramatic depictions of dementia. Knowledge about the trajectory of the disease and the structure of the brain was highlighted as crucial for understanding and developing coping mechanisms. Regarding gaining an understanding of the parent’s changing behaviour, participants observed that this occurred primarily when the children and young adults met in groups. In some cases, participants described that they represented the children and young adults in order to create contacts to receive knowledge and support from society, which included applying for grants and support for the parent, etc.

“It is quite clear that if you have knowledge, it is easier to support in a way. . . you feel more secure if you have knowledge.” (P.5)

4.3.3. Tailoring Support to Meet Needs. Participants described how support offered by society was not always adapted to the children’s and young adults’ needs. It was primarily designed and constructed for adult family caregivers. This was also evident in the organizational structures and the reluctance of other professionals to cooperate in delivering support to these children and young adults.

Children and young adults were considered as a specific nonhomogenous group, with a wide spectrum of needs. Emotional support for the children and young adults was described as a means of lightening the burden of caring for their parent. Emotional support was offered through formal and informal meetings helping and guiding the children and young adults at various levels and in various situations even after the death of the parent. Participants highlighted their commitment to trying to tailor support offered to the needs of the children and young adults.

“Well what’s the difference? The others are adults (referring to the how the support services are structured) . . . There is a sense of wanting to protect these children and young adults. If we don’t see them then who will. . .” (P.7)

The participants stated that their function in many ways resembled a bridge, or a sluice, where they could offer guidance and passage to the right type of support or function. This support could entail meeting a professional from the municipality, or tips about a website, or some type of equipment. An obstacle identified was the reluctance of

some children and young adults to converse with adult professionals. Attendance at summer camps, which were designed specifically for children and young adults with a parent with dementia, was successful in offering opportunities to talk and have contact with peers and professionals. Participants also spoke about support available via social media and through contact networks for young adults in similar situations. However, access to this type of support varied throughout the country with the absence of such support in small municipalities.

4.4. Building Trust and Relationships. Building trust and relationships with the children and young adults was described as important to gain an insight and understanding of the situation. Building a trusting relationship took time, effort, and long-term engagement. The key to successfully building and establishing a trusting relationship is further described in the three categories: *Having a flexible approach*, *Being competent and having confidence*, and *Creating a safe environment*.

4.4.1. Having a Flexible Approach. Participants spoke about various forums they had created or worked within to support young adults and children. Due to the diversity of the group, it was important to tailor the structure of the meeting according to the age of the children and young adults involved. This required a flexible and creative approach when organising meetings. For example, one participant used drawing and painting during a conversation with a child and young adult to enhance communication through a shared activity. Regardless of the chosen approach, it was above all important that the children and young adults felt comfortable and could guide the conversation at their own pace.

“When it comes to children and young adults you don’t carry on like you would if you had a group of older people where you just sit and talk without doing any activity at the same time. With the children you can paint and talk simultaneously allowing the children to take commando of the situation.” (P.10)

Other participants identified the importance of meeting the entire family to connect with the children and young adults. In one clinic, people who had recently received cognitive diagnoses were invited, with their families, to a mingle evening at the clinic. This was regarded as a successful way to establish contact and build relationships with the families and the children and young adults and share information about support groups, etc.

4.4.2. Being Competent and Having Confidence. In supporting the children and young adults, it was important to be focused and engaged and nonjudgmental. Staff and service continuity were regarded as key aspects in building trust and relationships with the children and young adults.

Some participants felt confident in their roles and spoke about working from intuitive experiences as opposed to having an agenda. Conveying confidence and being a good

listener when meeting with the children and young adults were essential. It was also important for the participants to know their limitations. For example, in situations where the children and young adults needed support for self-destructive behaviours, the social-care workers described the importance of guiding them to the appropriate support service.

To build a trusting relationship included affirming the severity of the child's and young adult's situation, that they were living with a parent with a serious disease. Being honest and maintaining a professional approach without offering false hope was vital in establishing trust.

"A lot is about daring. . . to be honest in a balanced way. You cannot sit and say that this is to work out or something like that, but it's about serious diseases. From my point of view, it is important not to give false hope that things will get better." (P.12)

Lack of confidence and competence was described as impacting on meetings with the children and young adults, resulting in conversations at a more superficial level. For meaningful meetings, it was important to be equipped to hold conversations that embraced the real challenges and dilemmas the children and young adults were facing.

4.4.3. Creating a Safe Environment. As home life and environment were regarded as playing important roles in providing stability, comfort, and support, participants were eager to gain insights into the children and young adults' home situation. Participants explained how it was important to create a safe and accepting environment for the children and young adults. Promoting civil rights and the right to live their life independently despite their family situation was highlighted. It was important to have knowledge of the children's/young adults' help-seeking behaviour, which was not always easily identified, and guide them to the services they were likely to use.

To assess the home environment, it was important for the participants to make home visits and gain an intimate view of the family's situation and foster relationships. Home visits helped build a picture of the children and young adults' home life and assess child protection issues for those aged under 18 years. Despite the importance of home visits, it was described that most of the children and young adults preferred to meet the social care worker at their office.

The participants who worked at summer camps also explained how they did their best to create a safe and accepting environment for the children and young adults. The camp participants could understand and relate to each other's situation, and the staff were all well versed. During the time at the camp, the children and young were encouraged to get to know each other and have fun.

"They open up. . . but you can sort of let them be. . . so they can have fun, play football. . . I spend a lot of time with them and am totally engaged" (P.2)

After attending the summer camps, many of the children and young adults become members of the "Young Relatives

Network" (in Swedish SNUA). This organization enables them to keep in touch with each other and exchange experiences.

5. Discussion

This is one of the first qualitative studies to describe health and social care professionals' experiences of identifying and supporting children and young adults with a parent with dementia. The overarching theme *Advocating a forgotten group* represents the main findings of this study. The diversity of dementia, family prerequisites, social and economic factors, etc., means that there is no one typical situation for a family living with dementia. Children and young adults may struggle to understand the impact of the consequences of dementia on their own lives and how to support their parents. The present findings highlight a need to develop support services tailored specifically for the needs of these children and young adults; this is in line with previous research [14].

In the present findings, health and social care professionals who encountered children and young adults with a parent with dementia described that they were not sufficiently trained in supporting this group and that there was a general shortage of appropriate services available. Similar experiences were voiced by Canadian nurses in a study conducted by Newman et al. [18], who highlighted a need for developing support in the form of online support resources, which are often preferred by young users due to accessibility and anonymity, which in reality is less associated with stigma than face-to-face meetings. The study by Masterson-Algar and colleagues highlights a need to garner support for adult carers in relation to structure, design, context, language, and content to fit younger users [31].

Health and social care professionals described how they offered and provided different types of support to children and young adults in the form of emotional support, including family and networking, providing illness-related information, practical skills, counselling, and possibilities of connecting with peers. This is in keeping with the research carried out by Frech et al. [20] who investigated support provided by professionals in education, health care, and social care. In this study, connecting with peers was seen, in the summer camps, as a powerful tool to increase knowledge and self-efficacy of the children and young adults with a parent with dementia.

Participants in this study did not mention the use of standardised questionnaires or checklists in their work to help identify and support children and young adults. However, they highlighted frequently a general necessity to strengthen the identification process of children and young adults with a parent with dementia. The children and young adults were described as a forgotten and overlooked group in need of affirmation in a more systematic way. Previous research has shown that professionals consider standardised questionnaires and checklists as helpful in identifying and supporting children and young adults who care for a person with dementia [18, 19]. It is likely that the use of questionnaires in practice could contribute to a greater awareness

of the existence and needs of children and young adults with a parent with dementia, and to establish support. However, our findings indicate that there is also a need for authorities to clarify the responsibilities and forms of support given by various providers.

Our findings show how efforts were made by participants to locate children and young adults to a parent who had received a dementia diagnosis and identify their needs. This was viewed as empowering the children and young adults who were otherwise regarded as an unheard group. Chirico et al. [32] highlight the significance of providing counselling and support to the persons and their families upon receiving a diagnosis of dementia, to aid in their adjustment to the situation. Nordenfors et al. [8] describe young caregivers in Sweden as a hidden population whose situation is not a topic of discussion.

Our findings also highlight how children and young adults did initiate contact with the school counsellor as there was a reluctance to stick out among peers by visiting the counsellor during school time. The broad spectrum of age both of parents and children and young adults makes them a heterogeneous group with a variety of needs. The complexity of the situation was described as impacting on most parts of the children's and young adults' everyday lives. When young adults lack parental guidance and support in their life, it can undermine their physical, psychosocial, and emotional development [21, 33]. Each child or young adult described required individual strategies for support, with the participants working beyond their role of duty to achieve this. Previous research [16] promotes the need to develop support services tailored to the needs of children and young adults living with parents with dementia.

It is also argued how the situation may have a disruptive effect on the children's physical, emotional, cognitive, and social development [33]. Previous research of young adults' experiences of parental dementia shows that it can lead to significant emotional, mental, and psychological issues and have an enduring impact on lives [10, 34].

The Swedish Health Care Act [25] states that children's and young adult's needs as a relative should guide the support. Although the target group children and young adults as relatives is not explicitly mentioned in the Swedish Social Act, the municipalities have according to other provisions in this law responsibility for children and young adults to have a safe upbringing, protection and support, and also for preventive efforts. Patton [23] highlighted barriers related to restrictive legislative frameworks, stigma, and community attitudes. Our findings show how the legislative framework in Sweden evoked some frustration among professionals creating difficulties to work as a team across the legal boundaries.

Viewing children and young adults with a parent with dementia as a forgotten group is in line with previous research on children and young adults who are supporting an ill parent (e.g. [9]), despite the rising awareness in research and policy-making of the vulnerability of this group [9, 27]. Finally, our findings indicate that there is still a need to increase the efforts to identify and support these children

and young adults. It is important to add that there are also potentially positive aspects to caregiving which have not been in the spotlight in this study.

5.1. Limitations and Strengths. The limitations and strengths of this study have been highlighted following Lincoln's and Gubas' [35] methodology of ensuring quality in qualitative research using their four criteria for trustworthiness. These criteria are essential for evaluating the rigor and reliability of qualitative studies while focusing on confirmability, credibility, dependability, and transferability. There were only 12 female participants and 1 male participant in the study, which can be considered as a limitation. However, most health and social care personnel are females [36]. This in turn is representative of the participants in this study. Regarding the number of participants interviewed in a qualitative study, it is not possible to suggest in advance a specific number of interviewees or interviews according to Graneheim et al. [37]. It is the aim of the study which steers the optimal amount of data gathered. The inclusion of a large number of participants in a study does not guarantee rich data [37]. Furthermore, there are also a limited number of health and social care professionals supporting children and young adults with a parent diagnosed with dementia in Sweden.

Five of the authors carried out the interviews. This can be viewed as a methodological limitation due to possible variations in interview styles and in interviewer-interviewee relationships. In recognising these potential variations, interviews and data collection were discussed within the team. Furthermore, an interview guide was used, and all interviews were audio-recorded with no significant variations noted. Three researchers conducted the analysis and engaged in discussions with all authors after which consensus was reached. This, in turn, enhanced the confirmability of our study. In addition, the detailed description of the context and inclusion of relevant quotations further contribute to the study's robustness and credibility. Strengths of this study are the diversity of participants' professions and geographical diversity. To enhance trustworthiness, a pre-designed and tested topic guide was used, and to establish dependability, the analysis process is explained in detail.

The possible transferability to other settings is an area which needs to be considered due to differences in legislations and organizational prerequisites between Sweden and other countries. By providing a detailed description of the study context and clearly outlining the central assumptions, it enhances the reader's ability to assess whether the study results are transferable to other contexts or situations. Research (SRQR) guidelines according to O'Brien et al. [38] have been used to improve the transparency of this study.

6. Conclusion

Health and social care professionals who encountered children and young adults with a parent with dementia described that they were not sufficiently trained in

supporting this group and that a general shortage of available appropriate services existed. Children and young adults with a parent with dementia were also described as a forgotten and overlooked group in need of affirmation and support in a more systematic way.

Data Availability

The data used to support the findings of this study are available from the corresponding author upon reasonable request.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

Acknowledgments

This work was supported by the The Norhed Foundation. Our deepest gratitude to the study participants who openly shared their experiences.

Supplementary Materials

The SRQR guidelines [38] have been followed, and the SRQR checklist for this study is attached. (*Supplementary Materials*)

References

- [1] S. Gauthier, P. Rosa-Neto, J. A. Morais, and C. Webster, *World Alzheimer Report 2021: Journey through the Diagnosis of Dementia*, <https://www.alzint.org/u/World-Alzheimer-Report-2021.pdf>, Alzheimer's Disease International, London, UK, 2021, <https://www.alzint.org/u/World-Alzheimer-Report-2021.pdf>.
- [2] World Health Organization [Who], *Global Action Plan on the Public Health Response to Dementia 2017–2025*, World Health Organization, Geneva, Switzerland, 2017, <https://www.who.int/publications/i/item/global-action-plan-on-the-public-healthresponse-to-dementia-2017---2025>.
- [3] A. Hillman and J. Latimer, "Cultural representations of dementia," *PLoS Medicine*, vol. 14, no. 3, Article ID 1002274, 2017.
- [4] S. Hendriks, K. Peetoom, C. Bakker et al., "Global prevalence of young-onset dementia: a systematic review and meta-analysis," *JAMA Neurology*, vol. 78, no. 9, pp. 1080–1090, 2021.
- [5] K. Fatima, A. M. Mehendale, and H. Reddy, "Young-onset dementia and neurodegenerative disorders of the young with an emphasis on clinical manifestations," *Cureus*, vol. 14, no. 10, Article ID 30025, 2022.
- [6] E. Odzakovic, L.-C. Hyden, K. Festin, and A. Kullberg, "People diagnosed with dementia in Sweden: what type of home care services and housing are they granted? A cross-sectional study," *Scandinavian Journal of Public Health*, vol. 47, no. 2, pp. 229–239, 2019.
- [7] National Board of Health and Welfare [Nbhv], "Anhöriga som vårdare eller stödjer någon de står nära: Underlag till en nationell strategi. [relatives as caregivers or supporting someone they are close to: basis for a national strategy] socialstyrelsen," 2021, <https://www.socialstyrelsen.se/globalassets/sharepointdokument/artikelkatalog/ovrigt/2021-6-7464.pdf>.
- [8] M. Nordenfors, C. Melander, and K. Daneback, "Unga omsorgsgivare i sverige [young carers in Sweden]. Kalmar: nationellt kompetenscentrum anhöriga," https://anhoriga.se/globalassets/media/dokument/publicerat/rapporter/unga_omsorgsgivare_kortversion_2017.pdf.
- [9] A. Leu and S. Becker, "A cross-national and comparative classification of in-country awareness and policy responses to 'young carers,'" *Journal of Youth Studies*, vol. 20, no. 6, pp. 750–762, 2017.
- [10] C. R. Gelman and K. Rhames, "In their own words: the experience and needs of children in younger-onset Alzheimer's disease and other dementias families," *Dementia*, vol. 17, no. 3, pp. 337–358, 2018.
- [11] C. Blake and L. Hopper, "Childhood perspectives of parental young onset dementia: a qualitative data synthesis," *Dementia*, vol. 21, no. 4, pp. 1304–1327, 2022.
- [12] A. V. Cartwright, C. R. Stoner, R. D. Pione, and A. Spector, "The experiences of those affected by parental young onset dementia: a qualitative systematic literature review," *Dementia*, vol. 20, no. 7, pp. 2618–2639, 2021.
- [13] I. Chirico, G. Ottoboni, M. Valente, and R. Chattat, "Children and young people's experience of parental dementia: a systematic review," *International Journal of Geriatric Psychiatry*, vol. 36, no. 7, pp. 975–992, 2021.
- [14] Å. Grundberg, J. Sandberg, and Å. Craftman, "Children's and young adults' perspectives of having a parent with dementia diagnosis: a scoping review," *Dementia*, vol. 20, no. 8, pp. 2933–2956, 2021.
- [15] C. Poole and T. G. Patterson, "Experiences and needs of children who have a parent with young onset dementia: a meta-ethnographic review," *Clinical Gerontologist*, vol. 45, no. 4, pp. 750–762, 2022.
- [16] M. Hall and P. Sikes, "It would be easier if she'd died: young people with parents with dementia articulating inadmissible stories," *Qualitative Health Research*, vol. 27, no. 8, pp. 1203–1214, 2017.
- [17] K. Hutchinson, C. Roberts, M. Daly, C. Bulsara, and S. Kurrle, "Empowerment of young people who have a parent living with dementia: a social model perspective," *International Psychogeriatrics*, vol. 28, no. 4, pp. 657–668, 2016.
- [18] K. Newman, S. Bookey-Bassett, and A. Ze Wang, "Exploring nurses' knowledge, skills and experience with young caregivers," *Perspectives: The Journal of the Canadian Gerontological Nursing Association*, vol. 42, no. 2, pp. 7–15, 2021, <https://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=160387947&site=ehost-live>.
- [19] A. Leu, M. Frech, and C. Jung, "You don't look for it—a study of Swiss professionals' awareness of young carers and their support needs," *Health and Social Care in the Community*, vol. 26, no. 4, pp. e560–e570, 2018.
- [20] M. Frech, H. Wepf, M. Nagl-Cupal, S. Becker, and A. Leu, "Ready and able? Professional awareness and responses to young carers in Switzerland," *Children and Youth Services Review*, vol. 126, Article ID 106027, 2021.
- [21] World Health Organization, "Adolescence: A Period Needing Special Attention. Recognizing Adolescence," 2014, <https://apps.who.int/adolescent/second-decade/section2/page7/implications-for-policies-and-programmes.html>.
- [22] Sbu [Swedish Agency For Health Technology Assessment And Assessment Of Social Services], "Inventering av vetenskapliga kunskapsluckor inom psykisk ohälsa 2005–2020 – insatser för att utreda, diagnostisera, förebygga och behandla psykisk ohälsa,

- inklusive stödjande och organisatoriska åtgärder (Rapport 335.) [Inventory of scientific knowledge gaps within mental health 2005–2020 – efforts to investigate, diagnosis, prevention, and treatment of mental health issues, including supportive and organizational measures]. Statens beredning för medicinsk och social utvärdering.” 2021, <https://www.sbu.se/sv/publikationer/sbu-bereder/inventering-av-vetenskapligakunskapsluckor--inom-psykisk-ohalsa-20052020/?pub=69307&lang=sv>.
- [23] M. Q. Patton, *Qualitative Research and Evaluation Methods*, Sage, England, UK, 4th edition, 2015.
- [24] SFS 2001:453, “Socialtjänstlag [social services act]. Riksdagen,” 2001, https://www.riksdagen.se/sv/dokumentlagar/dokument/svenskforfattningssamling/socialtjanstlag-2001453_sfs-2001-453.
- [25] SFS 2017:30, “Hälso- och sjukvårdslag [health care act]. Riksdagen,” 2017, https://www.riksdagen.se/sv/dokumentlagar/dokument/svenskforfattningssamling/halso--och-sjukvardslag-201730_sfs-2017-30.
- [26] SFS 2018:1197, “Lag om Förenta nationernas konvention om barnets rättigheter [Law concerning the United Nations’ Convention on the Rights of the Child]. Riksdagen,” 2018, https://www.riksdagen.se/sv/dokument-lagar/dokument/svenskforfattningssamling/lag-20181197-om-forenta-nationernas-konvention_sfs-2018-1197.
- [27] National Board of Health and Welfare [Nbhv], “Barn som anhöriga: konsekvenser och behov när föräldrar har allvarliga svårigheter, eller avlider. [Children as relatives: consequences and needs when parents face severe difficulties or have died] Socialstyrelsen,” 2013, <https://www.socialstyrelsen.se/globalassets/sharepointdokument/artikelkatalog/kunskapsstod/2013-6-6.pdf>.
- [28] U. H. Graneheim and B. Lundman, “Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness,” *Nurse Education Today*, vol. 24, no. 2, pp. 105–112, 2004.
- [29] World Medical Association, “WMA declaration of Helsinki: Ethical principles for medical research involving human subjects,” 2013, <https://www.wma.net/policies-post/wmadeclaration-of-helsinki-ethical-principles-for-medical-research-involving-humansubjects/>.
- [30] International Committee of Medical Journal Editors, “Recommendations for the conduct, reporting, editing, and publication of scholarly work in medical journals,” 2022, <https://www.icmje.org/icmje-recommendations.pdf>.
- [31] P. Masterson-Algar, K. Egan, G. Flynn et al., “iSupport for young carers: an adaptation of an e-health intervention for young dementia carers,” *International Journal of Environmental Research and Public Health*, vol. 20, no. 1, p. 127, 2022.
- [32] I. Chirico, G. Ottoboni, S. Linarello, E. Ferriani, E. Marrocco, and R. Chattat, “Family experience of young-onset dementia: the perspectives of spouses and children,” *Aging & Mental Health*, vol. 26, no. 11, pp. 2243–2251, 2022.
- [33] P. Sikes and M. Hall, “It was then that I thought whaat? This is not my Dad: the implications of the still the same person’-narrative for children and young people who have a parent with dementia,” *Dementia*, vol. 17, no. 2, pp. 180–198, 2018.
- [34] J. Allen, J. R. Oyeboode, and J. Allen, “Having a father with young onset dementia: the impact on well-being of young people,” *Dementia*, vol. 8, no. 4, pp. 455–480, 2009.
- [35] Y. Lincoln and E. Guba, *Naturalistic Inquiry*, Sage Publications, Newbury Park, CA, USA, 1985.
- [36] Eurostat, “Majority of health jobs held by women,” 2021, <https://ec.europa.eu/eurostat/web/products-eurostat-news/-/EDN-20210308-1>.
- [37] U. H. Graneheim, B.-M. Lindgren, and B. Lundman, “Methodological challenges in qualitative content analysis: a discussion paper,” *Nurse Education Today*, vol. 56, pp. 29–34, 2017.
- [38] B. C. O’Brien, I. B. Harris, T. J. Beckman, D. A. Reed, and D. A. Cook, “Standards for reporting qualitative research: a synthesis of recommendations,” *Academic Medicine*, vol. 89, no. 9, pp. 1245–1251, 2014.