

The impact of COVID-19 on the lives of community-dwelling people with dementia and informal carers in the context of using the social and medical services – a qualitative study

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Abstract

Background:

Older people with dementia are particularly at risk of COVID-19, whilst still little is known about the indirect impact of the Pandemic on the lives of those living with and caring for someone with dementia. The aim of this study was to investigate the impact of the Pandemic on the lives of people with dementia and their informal carers in the context of using social and medical services in Poland.

Methods:

A qualitative thematic analysis of semi-structured interviews with people with dementia (n = 5) and informal carers (n = 21) was performed. Interviews were collected between June and August 2020 via phone after the first wave of COVID-19 in Poland. Data were analysed using NVivo software by four team members.

Results:

Three overarching themes emerged: (1) Care re-organization; (2) Psychological responses; (3) Emerging needs. The factor underlying all these elements were a reliance on other people. Regardless of the type of support (informal or formal), a sense of presence of others and maintaining mutual contacts displayed as crucial elements influencing the well-being of people with dementia and informal carers.

Conclusions:

Social support and engagement are vital to the ongoing health and wellbeing of people living with dementia and their informal carers. Services need sustaining to provide ongoing provision to those living with dementia to reach pre-pandemic levels, if not better. Within the post-pandemic environment people with dementia and their informal carers need reassurance that they can rely on external institutional and social support able to meet their need.

Background

From the end of 2019 until now, the world is struggling with the coronavirus Pandemic. By focusing effort to halt the spread of infection many social sectors have been relatively neglected (1–3). Although the various consequences of the Pandemic concern numerous social groups (4), they incommensurately affect older people who, as well as being most vulnerable to serious infection and its negative consequences, are most dependent on outside medical and social support (2,5,6). Among older adults a significant group affected by the coronavirus outbreak are people with dementia, who experience a wide range of intense caring needs irrespective of the current epidemiological situation (7). Supportive and

predictable environments, feelings of being accompanied, receiving social help and obtaining medical consultation are crucial elements for people with dementia. They underpin a basic sense of security, prevent excessive disorientation and loss of sense of control. If these needs are not met, the disease progresses faster and the quality of life of people with dementia drops dramatically (3,6).

In Poland, in the face of insufficient system solutions and limited forms of institutional post-diagnostic support, this 'supportive environment' is usually created by the closest family of the person with dementia (8,9). Caring for an older person with cognitive impairment is itself a considerable source of a distress (10). The Pandemic has intensified this psychological response further (11). Informal carers were left alone with their caring responsibilities due to the reduction of all forms of support they previously obtained (12). For informal carers who are professionally active, switching to remote work became their only means to provide their relatives with necessary care. The circumstances of the Pandemic has often resulted in informal carers spending more time with their relatives, which could potentially enrich their relationship (13,14). However, this also imposed additional caring responsibilities upon them (13). Higher pressure put on informal carers elevated their stress level and has negatively influenced their overall psychological well-being. Those with lower levels of resilience were even more liable to experienced increase mental health symptoms, such as anxiety and depression (15). Although evidence highlights the negative consequences of the Pandemic on the informal carer's role, for others it reinforced their existing isolation from the mainstream society as a consequence of their caregiving role (16,17).

The aim of this study was to investigate the impact of the COVID-19 Pandemic on the lives of people with dementia and their informal carers in the context of using available social and medical services in Poland. Previous studies (11,16,18) provided insight into the Pandemic effects on selected aspects of the psychological functioning of people with dementia and their informal carers, but few related these phenomena directly to the issue of using care services during the Pandemic (19,20). Moreover, to date there is no evidence of the Pandemic's impact on those affected by dementia in Poland.

Methods

Study design

A qualitative design was applied in this study to investigate the impact of COVID-19 Pandemic on the lives of people with dementia and informal carers in the context of using social support and medical services.

Participants and recruitment

Informal carers aged 18+ who were caring a person with dementia and people with dementia (with capacity to consent and participate) accessing social care and/or social support services were enrolled in the study. Social care and social support services included: day care facilities, support groups, home rehabilitation, befriending services, visiting social worker, meal delivery, and home care. The participants

were recruited via outpatient memory clinics and day care facilities in the city of Wroclaw, Poland (the 4th largest urban agglomeration in Poland with an estimated population of over 64 thousand) (21).

Data collection

Informal carers and people with dementia who were interested in taking part in the study were contacted by telephone and invited to participate in a semi-structured telephone interview, and consented if still willing. The interviews were conducted by psychologists and psychiatrists between June and August 2020, after the first wave of COVID-19, when Pandemic restrictions in Poland were eased.

Semi-structured interviews were adapted from a parallel study conducted by Giebel et al. (2020) during April 2020 (19). A topic guide, containing questions about service use before and since the Covid-19 outbreak, was translated according to the WHO translation protocol (22), which included a forward translation, a panel of experts, back translation, pre-testing, and creation of the final version (23). Each interview was audio-recorded, the mean interview length was $M = 18$ min ($SD = 6$ min 14 s).

Data analysis

Recorded interviews were transcribed into verbatim scripts by the research team members experienced in preparing materials for qualitative analyses. Prior to analysis, all transcripts were anonymized and proofread. Reviewing the transcripts for correctness was itself a stage of the authors' familiarization with the data. Four researchers analysed the data – three psychologists and one psychiatry resident. The transcripts were analysed by applying thematic analysis – both inductive and deductive (24) with regard to the main analytical question: 'What is the impact of Covid-19 Pandemic on the lives of people with dementia and informal carers in the context of using the dementia-related services?' Analyses were conducted separately for informal carers and for people with dementia.

At the first stage, the most information-rich transcripts of interviews with informal carers and people with dementia were analysed independently by two researchers who developed initial codes (inductive analysis). In the discussion between researchers the codes were made uniform and gathered into codebook. Based on this jointly-developed codebook, the remaining material was analysed by one of the researchers (deductive analysis). Transcripts' coding was performed using NVivo software. Finally, researchers formulated themes from the coded data, with all authors, familiarised with the transcripts and codes, discussing the themes until agreement on them was reached.

The interviews, transcription and analysis were conducted in Polish. The results are reported in English. All the quotes cited were subject to the back translation to ensure the correct transfer of meaning between languages.

Results

Participant demographics

We completed 26 semi-structured interviews with informal carers (n = 21) and people with dementia (n = 5). Most participants were female (65%). The majority of informal carers (62%) were living with the people with dementia and were adult children (71%). Dementia subtypes included: Alzheimer's disease (39%) mixed dementia (31%), vascular dementia (15%) dementia in Parkinson's disease (4%) and dementia not further specified (12%). The mean age of people with dementia was 81 years old with their average period of education consisting of 13 years. Participant demographics are summarised in Table 1.

Table 1
Demographic characteristics of people living with dementia and informal carers

N (%)	INFORMAL CARERS (n = 21)	PEOPLE WITH DEMENTIA (n = 5)	Total sample (n = 26)
Gender			
Female	13 (61.9%)	4 (80%)	17 (65.4%)
Male	8 (38.1%)	1 (20%)	9 (34.6%)
Relationship with PLWD			
Spouse	6 (28.6%)	-	-
Adult child	15 (71.4%)	-	-
Living with PLWD			
Yes	13 (61.9%)	-	-
No	8 (38.1%)	-	-
Dementia subtype			
Alzheimer's disease	8 (38.1%)	2 (40%)	10 (38.5%)
Mixed dementia	6 (28.6%)	2 (40%)	8 (30.8%)
Vascular dementia	4 (19%)	0 (0%)	4 (15.4%)
Not specified	2 (9.5%)	1 (20%)	3 (11.5%)
Dementia in Parkinson disease	1 (4.8%)	0 (0%)	1 (3.8%)
Mean (SD), [Range]			
Age	* 81.5 (+/-4.7) [75–85] ** 63.1 (+/-9.9) [52–80]	78 (+/- 6.6) [70–87]	80.8 (+/- 5.14) [70–87]
Years of education	12.9 (+/- 2.92) [9–17]	10.8 (+/-1.64) [9–12]	12.5 (+/- 2.82) [9–17]

* Age of people with dementia living with/cared for by informal carers; ** Age of informal carers

Qualitative themes

Thematic analysis resulted in three main themes with several sub-themes. Themes were common between informal carers and people with dementia: (1) Care re-organization; (2) Psychological response; (3) Emerging needs. Arrangement of the themes and sub-themes is illustrated in Fig. 1. Only the most representative quotes are presented in the text. More examples are available in Additional file 1.

Figure 1. Themes and sub-themes

Theme 1: Care re-organization

Restrictions imposed due to the Pandemic outbreak caused significant changes in the organization of care for people with dementia. To avoid contact with potential virus carriers people with dementia withdrew from most of their daily activities, including attendance at day care facilities. Consequently, informal carers were tasked with providing intensified care to their relatives. These changes gave rise to various personal responses to the Covid-19 situation.

Burden of care

Facing service closures and for fear of exposing older adults to the virus, many informal carers decided to strictly limit the number of contacts for their relatives. The duty of care usually fell on the closest person (children or a spouse) who could not count on any replacement or respite care resources. Participants underlined that it was a substantial organizational and emotional burden.

If the carer has an institution where parents spend their time and suddenly this institution closes, then it has a negative effect on their organization of life, right?

Female Informal Care, 58, Daughter, Interview 16

My daughter always said: 'Mum, you are going out - don't go out!' So as to avoid this event.

Female, Person with dementia, 70, Interview 5

Shutdown or restrictions on operation of day care facilities

Differences in care organization during the Pandemic were especially noticeable to those participants who were beneficiaries of social care facilities before. Day-to-day activities in a peer-group and professional support turned out to be priceless and indispensable. Lack of regular schedule, hours spent alone and restrictions to their own home were distressing for people with dementia and also influenced informal carers. They became unable to divide their care responsibilities and were worried that they would not provide enough cognitive, social and physical stimulation to their relatives.

What I felt when the closed the day care facility? It was stress. And it still is. We had to organize something that worked well again. I didn't know when it would end, how we should work with mum, so

that what was achieved in Senior Plus [daily care home] wouldn't be wasted. We share the care with our sister, but it can be difficult.

Female Informal Carer, 65, Daughter, Interview 7

As we were closed and not able to meet with others, it just felt like prison. It was hard to handle.

Female, Person with dementia, 82, Interview 1

Access to medical help

Participants unanimously emphasized that COVID-19 had become a priority for the entire healthcare system with other medical conditions sidelined. As a result, access to medical care was often challenging, especially for people with dementia and other comorbidities. Interviewees pointed to the barriers in accessing teleconsultations, which included waiting queues. Older adults highlighted the importance of a doctor's physical examination. The lack of it caused uncertainty about diagnosis and a sense of a decrease in the quality of care. Nevertheless, some participants were satisfied with telemedical solutions. This was largely dependent on the dedication of medical personnel in each facility.

I haven't had any revolution in my life because there are telephones and I could always call for help and ask. We also have clinics here, the health care team, which is very dynamic. They are even so determined to help patients that they took us in during a pandemic when my husband's blood sugar was too high.

Female Informal Carer, 77, Wife, Interview 19

I wish the access to medical care was better.

Female, Person with dementia, 76, Interview 4

Theme 2: Psychological response

Changes in organization of everyday life and unknown, unpredictable situations, initiated the process of adaptation to changed life circumstances. This process triggered different emotional reactions in informal carers and people with dementia and resulted in various attitudes and individual consequences – from difficulties in adapting to the situation to implementing positive coping strategies.

Uncertainty and anxiety

Participants experienced many negative emotions evoked by the Pandemic crisis. Fear of being infected combined with the additional caring duties or self-isolation resulted in an apparent decline of respondents' mental health. Informal carers reported increased levels of distress related mostly to their concerns about their relative with dementia. For people with dementia pressure to stay at home increased their sense of helplessness, lack of agency and anxiety.

„It was very sad. I was lying on my bed and staring at the wall. Every day. How many people died and where? It was very sad. It lasted for so long.“

Female Informal Carer, 58, Daughter in-law, Interview 10

Well, I got a little stressed [with the lockdown], because it is a kind of burden. If I need something, some help, there is no way to get it. If I call a doctor, it is also impossible to get to him. And it's even hard to get a prescription.

Female, Person with dementia, 76, Interview 4

Loneliness

Physical distancing did not only impact on the organizational aspects of life. It also brought on the emotional void and intensified the sense of loneliness, which particularly affected older adults. Informal carers felt powerless in the face of the adverse consequences of social isolation on their relatives. They were observing apprehensively the decline in overall functioning of people with dementia including cognitive skills, emotional well-being and physical functioning. They were concerned whether people with dementia would ever be able to return to the pre-Pandemic levels of mental and physical health.

Literally, very soon after the day care facility was closed, my mother started to deteriorate in her health, especially the mental one. Her behaviours started to change, a lot of problems grew and for me it was a very big problem. I had to hire a private carer very quickly."

Female Informal Carer, 58, Daughter, Interview 1

I am used to being lonely. Even before that virus I lived a life of a lonely person as I had been caring for my wife for 25 years.

Male, Person with dementia, 87, Interview 2

Acceptance

Although the Covid-19 Pandemic negatively influenced many aspects of functioning, some people were able to adapt to the new circumstances. Their capacity for maintaining a mental balance depended on the adoption of positive coping strategies. Emotion-focused or problem-focused strategies seemed to be the most effective in positive passing through the adaptation process. It was notable the extent to which people with dementia adjusted to the sanitary recommendations and accepted imposed requirements.

I don't mind wearing masks if it's required

Male, Person with dementia, 87, Interview 2

If it weren't for the optimism, we couldn't deal with such problems.

Female Carer, Interview 9

Theme 3: Emerging needs

Pandemic-related changes and the process of adjusting to the new reality revealed important needs for people with dementia and informal carers. Participants indicated what was helpful in coping with the Pandemic situation, and what was missing but would be valuable.

Institutional support

Respondents claimed that institutional support during the Pandemic was not sufficient and often did not meet their expectations. Help from the welfare office or personnel of day care facilities was either absent or not adequate. Most of the informal carers had to organize everything themselves. Those who received some institutional support highly appreciated it.

Regarding the psychosocial interventions, unfortunately it was very poor. It is true that from time to time, personnel [of daily care home] sent some links to on-line exercises, but my mother cannot use it. She can't handle something like that, so it was unfortunately useless for her.

Male Informal Carer, 58, Son, Interview 15

Social support

Irrespective of institutional support, participants emphasized the indispensable importance of social support. Regardless of whether it was family, friends or neighbours – any support from others prevented people with dementia and informal carers from feeling left alone. Perception of other people's willingness to help was a vital factor influencing experience of the Pandemic period, notably reducing negative emotions.

Of course, we are supported by friends and family. It would be hard without it. Or even hopeless.

Female Informal Carer, 77, Wife, Interview 19

I have had thoughts how it's going to be like and if I can handle it. But what turns out is that there are people who remember me. And they help. And this is very important for me. And that's what they tell me: if you needed help, we would help you, just tell us.

Female, Person with dementia, 75, Interview 3

Remote contacts

Informal carers appreciated online forms of communication. For them it was a useful medium of connecting with people in a time of social distancing. The Internet (social media, on-line support groups) allowed them to receive information about providing dementia support and reduced loneliness. However remote forms of communication did not satisfy the needs of people with dementia. Engaging in remote communication was considered too technically challenging and did not offer emotional closeness to another person.

It [on-line support for carers via communicators such as Zoom, Skype] is important. Because if there is no direct possibility, then you just have to look for a solution and undoubtedly some social media or some platforms that allow you to contact, (and see another person, because it is the human face that has the power), it is important. It is a form that may not be perfect, but it is good enough to be used.

Female Informal Carer, 60, Daughter, Interview 17

„These teleconsultations... well, maybe they don't quite meet my expectations. Actually, mine and my husband's. Because we have a cold, for example, we want the doctor to see us, but to auscultate the throat, to take care of the patient in such a professional way.”

Female, Person with dementia, 70, Interview 5

Discussion

The study highlights the impact of the Pandemic's public health restrictions on the lives of people with dementia and informal carers and adds to a developing evidence base on the detrimental impacts of COVID-19 and associated restrictions on the lives of some of the most vulnerable members of society and their informal carers (19,25–28). Results reveal various aspects of the pandemic's consequences on peoples' lives and changes in their care needs.

Coronavirus restrictions suspended the functioning of the majority of care services available in Poland (29). Results from this study show that both people with dementia and informal carers had to re-plan their care and switch to remote ways of using social and medical services. The sudden changes created a variety of psychological responses, such as emotional distress or helplessness. This started the adaptation to the critical situation (30). The challenges posed by the Pandemic additionally revealed support needs – both institutional and social – which were helpful for better adaptation to life with dementia under the Pandemic regime (31).

The actual changes in the functioning of the health and social care systems reported in this study are comparable to actions taken by governments of countries struggling with the novel coronavirus around the world (32). Prioritizing stemming the spread of the virus left dementia care needs behind. This negatively affected the mental and social well-being of people with dementia and those who support them (12,33). In Poland even before the Pandemic the dementia care system was not well organized and the major burden of care issues was left to informal carers (8,9). As shown in our results, Pandemic restrictions added anti-virus protection tasks to their usual duties. Despite the extra effort put into caring, they considered the support offered was not sufficiently stimulating for people with dementia. Consequently, informal carers reported elevated physical and psychological strain. This adverse trend, according to the observations conducted so far, has become a common experience of informal carers around the world, regardless of the care system operating in a given country (18,27,34). Pandemic-related changes in the caring responsibilities lowered informal carers overall well-being, both mental and physical (17) such as sleep disturbances, anxiety or depression (35). Moreover, it increased the risk of

carer burnout (27). The intensity of these psychological reactions largely depended on intrapersonal factors such as their appraisal of the Pandemic risks and consequences and their ability to adopt coping strategies (30).

Among people with dementia, we also observed a burden, but of a different type. They felt trapped, isolated and totally dependent on other people. Talbot and Briggs (25) identified similar feelings referring them to the 'shrinking world' theory (36). COVID-19 escalated the dominant sensation following a dementia diagnosis, that the world of a person is narrowing. It deprived people with dementia of the social foothold and disrupted their regular activities, posing another loss (25). On the other hand, however, being restricted to the home may have offered relief from outside sources of anxiety and could prevent people from engaging with everyday activities (37). As a result people with dementia were deprived of the factors helping maintain their independence such as autonomy in dealing with everyday duties or not being treated by others in an overprotective manner (7,38–40). Uncertainty around the coronavirus added to the loss of the sense of control (41) and adversely affected the overall well-being of people with dementia (42–44). Lack of environmental stimulation caused by Pandemic restrictions turned out to be a considerable accelerator of decline in emotional and cognitive functioning (19,45). Research suggests a wide range of specific neuropsychiatric symptoms which are mediated by this form of imposed, elongated social isolation. Among them there are mood alterations, apathy, anxiety, reduced motor activity, appetite, circadian rhythm changes and psychotic symptoms (42,44,46–49). In our study, it was the informal carers who reported changes in the functioning of people with dementia. They observed most of those neuropsychiatric symptoms noted elsewhere (42,44,46,50) and attributed them with the imposed social isolation and closures of social services. In the face of these adverse psychological and psychiatric consequences it is important to note that both people with dementia and informal carers are exposed to increased social isolation regardless of the Pandemic restrictions (16,27,44). Ongoing crisis only heightens the risk of the negative effects of loneliness, thereby signaling the importance of social support in dementia care in general (42,51,52).

Despite the negative psychosocial consequences, our results show that people with dementia did not question public health guidance. This is in contrast to other studies highlighting the difficulty of persuading people with dementia to comply with public safety measures (31,53,54). This may be related to the characteristics of the study sample. Participants showed no behavioral disturbances and were in the early stages of dementia, which might have positively influenced their compliance due to increased levels of mental capacity and thus understanding the reasoning behind the need for public health measures (55).

The lack or the inadequacy of the support options reported in this study were associated with the transition to remote use of services and social contacts. In Poland, older adults, including people with dementia, are often alienated from technological progress (56), which caused difficulties in benefitting from remote support provision (33,57), including social and medical care. To date, knowledge about and usage of telemedicine in Poland has been limited (58). Testing this solution suddenly and widely during the lockdown highlighted barriers to its successful implementation (29). Apart from technical difficulties,

the obstacle was the general reluctance of people with dementia to engage with remote contacts. As highlighted by other studies, people with dementia experience difficulties in coping with lack of physical contacts and suffer its consequences (18,33). However, informal carers were more proficient in digital media use. Though they could benefit from possibilities offered by technology – both organizationally and emotionally (59–61). This is encouraging when the introduction of technological solutions to dementia care is inevitable (62,63).

Although our study gives a broad sense of various experiences of people with dementia and informal carers, some limitations need to be considered. There is a disproportionate number of carers who participated as opposed to people with dementia. This can result in the under-interpretation of varied experiences of people with dementia and limits the picture of the Pandemic situation from this specific point of view. Moreover, the recruitment strategy enabled us to only interview people living in Wroclaw which is among the largest cities in Poland, thereby excluding the experiences of people with dementia and carers residing in more rural areas, who are likely to be facing additional barriers in accessing care. Bearing these limitations in mind, extending this data collection to a larger sample, in wider living environments and with a greater proportion of people with dementia living in Poland (64). including exploring how place of residence determines the impact of the Pandemic on life with dementia. A further step would be to make international comparisons in order to explore how different health and social care systems have performed in the context of providing dementia care.

Conclusions

This appears to be the first study highlighting the detrimental impact of COVID-19 Pandemic on the lives of people with dementia and informal carers in the context of using social and medical services in Poland. Findings contribute to an emerging evidence (19,31,33,42,51) base on the urgent needs in dementia care highlighting the importance of social support and pointing out the malicious effects of its deprivation. Considering the inadequate state of dementia care during the Pandemic, and the early consequences already noted in people with dementia and informal carers, findings indicate an urgent requirement to fortify and extend social support and medical services to provide improved care for those affected by dementia, and their informal carers, especially in the light of the ongoing Pandemic. Despite vaccinations starting being rolled out in certain countries globally, the Pandemic will continue and services need to adapt flexibly and urgently to prevent further rapid deterioration among this vulnerable group.

Declarations

Ethics approval and consent to participate

The study was awarded ethical clearance from Wroclaw Medical University Ethics Committee (KB-366/220) prior to commencement, and was performed in accordance with the Declaration of Helsinki (65). Each interview was preceded by a recorded informed verbal consent of the participant.

Consent for publication

Not applicable.

Availability of data and materials

The data analysed during this study are included in this published article and its supplementary information files. The full transcripts of the interviews analysed in the study are available in Polish from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

CG and MG contributed to the conception and design of the study. MM, AS, ET, MoM, MC, RS were involved in recruiting participants, conducting and transcribing the interviews. MM, AS, MC, DS and MoM analyzed and interpreted the data. CG, MG, JR, DS, KL, ET, JM, substantively revised the work. MM was a major contributor in writing the manuscript. All authors read and approved the final manuscript.

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Figures

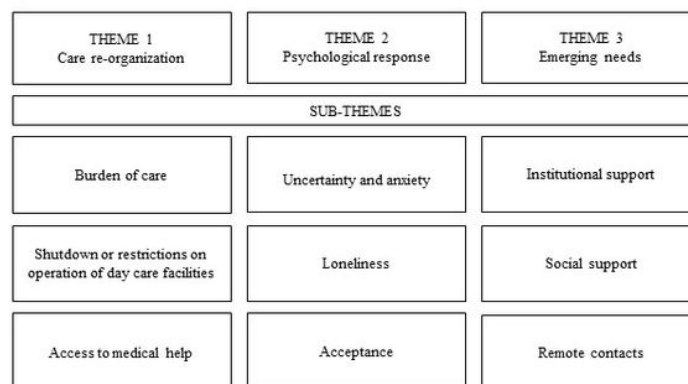


Figure 1

Themes and sub-themes

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