Needs assessment of informal caregivers supporting a person with dementia: a descriptive study of current practices

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Abstract

Background

Informal caregivers who support a person with dementia (ICDs) play an essential role in the healthcare system. Their intensive contribution puts them at high risk of negative consequences on their physical and psychological health. Despite significant unmet needs, ICDs rarely or only belatedly ask for support. Identifying these unmet needs is essential for a timely use of the relevant support services and for the prevention of exhaustion. Research about how diverse support providers assess the needs of ICDs is scarce. Our study aimed to describe current evaluation practices of support providers regarding needs assessment in one Swiss canton (province), in order to identify strengths and weaknesses.

Methods

A survey was completed by 55 professionals and volunteers involved in ICDs support with six open-ended and four closed questions investigating current practices for assessing the needs of ICDs.

Results

A diversity of providers assessing the needs of ICDs reported spending on average 45 minutes per assessment (range: 5-120 minutes). Most providers declared that they were reassessing the needs of ICDs (80%) and in most cases ICDs received some feedback after the assessment (86.5%). Few providers used a systematic procedure focused on ICDs (27.1%), and no validated tool with a focus on the needs of ICDs was used. Only 52.7% of providers reported having been trained in needs assessment. 41.8% described heterogeneous assessment procedures in their service, and the collected information was mostly stored in files related to the person with dementia (PwD) and not in a file directly attributed to the ICD.

Conclusion

Current practices in assessment of the needs of ICDs maintain the lack of coordination within the fragmented network of support providers, highlighting the need for policy thinking along the ICDs trajectory. As a first step towards improvement, providers need a cross-professional tool that allows for systematic and exhaustive assessment focused on the needs of ICDs.

Background

Thank to informal caregivers (ICDs), most persons with dementia (PwD) can fulfil their wish to live at home as long as possible. ICD involvement is also essential for the sustainability of healthcare systems, all the more so because the prevalence of dementia is expected to rise due to population ageing [1]. Being
an ICD involves a challenging journey spanning over several years, for which individuals are not prepared, and along which they need appropriate and timely support to reduce harmful consequences. Indeed, in all types of dementia, the affected persons become more and more dependent on the assistance, supervision and care of others due to their progressive decline in cognitive functioning and therefore in social abilities. On average, ICDs spend 5.7 hours a day in caregiving [2]. This voluntary involvement covers about 40% of the costs of dementia worldwide [2]. In 2019, 57 millions of individuals were living with dementia worldwide, and this number is expected to triple by 2050 in the absence of a cure [1], with over 10 million new cases each year [3]. In Switzerland, where the population is among the oldest on the planet, 144,300 persons were living with dementia in 2020, with one new person affected every 17 minutes [4]. For each PwD, between one and three ICDs - often the spouse and/or adult children - are directly involved in providing support [4]. Their voluntary contribution covers 47% of the costs of dementia in Switzerland [5]. Sustaining ICD involvement is a core public health issue while taking up an informal caregiver role is becoming more difficult due to shifting family structures (e.g. smaller family size, family members living further apart, stepfamily), as well as higher employment rates for women and increasing professional pressure on both genders [6]. Many ICDs experience long periods of chronic stress, reduced quality of life and social isolation, as well as more physical and mental health challenges, compared to their non-caregiving counterparts or to caregivers of persons without dementia [e.g. 7, 8]. ICD burden and health deterioration are core predictors of early institutionalisation [9] and mistreatment [10] of the PwD.

Supporting ICDs is in the interest not only of the person receiving the care, but also of the healthcare system and society in general. However, enabling ICDs to access services that meet their needs before they become exhausted is a challenge, as it requires the identification of needs, the referral to relevant services, and the provision of individualised support. In Switzerland as in many other high-income countries, a diversity of support options are available for PwDs and their ICDs, stemming from public, private and community initiatives. These support options involve diverse professionals including physicians (both general practitioners and specialists), nurses, social workers, psychologists (neuropsychologists, psychotherapists…), pharmacists, or occupational therapists. Another source of complexity lies in the fact that Switzerland has a high level of decentralisation, as it is composed of 26 cantons (provinces) with substantial independence in terms of health policy; most cantons are further divided into several districts, which may also have some independence regarding healthcare. A nationwide evaluation of publicly funded support for ICDs [11] revealed that most cantons in Switzerland provide key services for ICDs, however with substantial heterogeneity. For example, 65% of the cantons had homecare services with expertise in dementia in each district, while only 35% had specialized day-care or a specialized coordination service in each district. The lack of accessible and well-identified single points of contact is an additional challenge. In this context, networking and coordination have repeatedly been identified as the biggest challenges, contributing to the sub-optimal use of services (e.g. poor orientation by professionals due to the lack of knowledge of other services, competition between services, coordination left in the hands of ICDs) [12]. Another factor contributing to the underuse of services is that ICDs tend to ask for help only when they are exhausted or in a crisis [13], predominantly due to poor
identification of their needs and sometimes to the lack of knowledge about available services [14]. ICDs often fail to perceive their own needs as they are focused on those of the PwD [15].

However, when proactively questioned, ICDs report important unmet needs at all stages of the disease, suggesting that they require support to identify these needs, the extent of which is often underestimated by healthcare professionals. The needs of ICDs cover very diverse areas, such as information about the illness and support resources, support for their own emotional concerns, support in communicating with the care recipient, the family or service providers, practical support in daily care, financial support or respite (e.g. day-care centre) [16–22]. In Switzerland, a national survey of 2000 ICDs showed that two thirds reported important unmet needs in the area of daily life organisation or respite due to exhaustion, and half of ICDs had strong difficulties in managing the behaviour problems of the PwD, family relationships or the coordination of care [23]. There is also evidence that healthcare professionals underestimate the needs of ICDs and overestimate the extent to which these needs are already met. A systematic review showed that general practitioners considered that the needs of ICDs were generally met, despite acknowledging a lack of time and communication skills; In contrast, ICDs thought that the general practitioners mostly failed to meet their needs as they focused predominantly on the medical treatment of the PwD [24]. A Swiss survey conducted with homecare nurses and informal caregivers of elderly persons revealed that these professionals also underestimated the needs of informal caregivers: while about two thirds of the latter reported psychological distress, only one fourth of the nurses identified it [8, 25].

Very few studies have explored how the needs of ICDs are assessed in practice, pointing to an important gap in knowledge. A recent qualitative study [26] examined 20 interviews conducted by case managers with PwDs and their ICDs, aiming at needs assessment for both persons. It revealed that only a few needs were spontaneously and explicitly mentioned by the PwD or the ICD, while other needs were implicitly evoked but then neglected by the case manager despite his/her expertise. These results suggest that such a non-systematic assessment may overlook important needs and fail to guide ICDs in the identification of their needs. Another qualitative study in the UK comprised eight focus groups involving 40 healthcare professionals, and 22 interviews with informal caregivers, to explore the assessment process leading to hospital discharge of patients with a palliative condition [27]. Professionals identified that they focused primarily on the needs of the patient and on the practical aspects of homecare, which left little attention for the emotional aspects and for the needs of the informal caregiver. The needs of the latter were only perceived by the professionals in case of serious problems, while informal caregivers wanted their needs to be considered before difficulties arose. Professionals described "over-optimistic" expectations of caregivers regarding the challenges of homecare and the amount of formal support available at home, which limited caregivers’ anticipation of needs. Informal caregivers were convinced that a systematic evaluation of their needs would support them in identifying these needs in a situation which is new to them, and help them feel empowered to ask for support. Professionals also considered that a systematic procedure for assessing needs would facilitate discussion on this topic.
How do the diverse professionals involved in supporting ICDs evaluate their needs? Our study aimed at describing current evaluation practices in the Swiss canton of Fribourg, to identify strengths and weaknesses.

**Methods**

**Participants**

We recruited a convenience sample of professionals and volunteers involved in supporting ICDs in the canton of Fribourg (Switzerland). Inclusion criteria were 1) to be a professional or a volunteer in regular contact with ICDs, and 2) to conduct needs assessment with them. As the canton of Fribourg is bilingual (French and German), the study was conducted in both languages. Potential participants were invited by the members of a project support group, representing 27 local organisations, as well as through the research team’s contacts. We distributed electronic invitations, providing information about the study and the link to an online survey. An amount of CHF 40.- (approximately 43 USD, via bank transfer) was offered to each participant for completion of the full survey.

**Procedure**

The project protocol was submitted to the official local ethics review board (Commission cantonale d’éthique de la recherche sur l’être humain du canton de Vaud, CER-VD; request REQ-2017-00315), which declared that the project does not fall under the Swiss federal law on research on human beings and therefore required no authorisation.

All methods were carried out in accordance with relevant guidelines and regulations. All materials were submitted and validated by a panel of senior researchers, and were pre-tested with people who met the inclusion criteria. Informed consent was obtained from all participants in electronic format at the beginning of the survey. Data were collected from June to August 2019.

**Measures**

After choosing their language (French or German), participants were asked to complete three questionnaires.

*Background questionnaire.* This questionnaire collected data on participants’ background characteristics including gender, year of birth, duration and frequency of working with ICDs, occupation (employing organisation and position).

*Filter questions.* Two filter questions evaluated the inclusion criteria: Participants were asked 1) whether they had contact with one or more ICDs, and if so with approximately how many each year, and 2) whether they had assessed the needs of these ICDs.
Survey of current practices. The survey was developed specifically for this project. Six open-ended and four closed questions investigated current practices for assessing the needs of ICDs. These questions asked for 1) a description of current assessment practices, 2) whether a systematic procedure was used, 3) consistency of practices within their organisation, 4) training received regarding needs assessment, 5) average duration of a needs assessment, 6) frequency of reassessment, 7) feedback given to ICDs about their needs, 8) transmission of the collected information, 9) storage of the collected information, and 10) who had access to the stored information [for items and response options see Additional file 1].

Analytic strategy

Frequencies and percentages were calculated for the four closed questions of the survey, using the Statistical Package for the Social Sciences (SPSS), Version 26. Participants’ responses to the six open-ended questions were submitted to content analysis [28] using ATLAS.ti, Version 9, and coded into categories by two authors independently (NP and SP). Disagreements were resolved by discussion. For all categories, the percentage of participants was calculated; their sum may exceed 100% for questions with non-exclusive categories or fall short of 100% as some answers were out of scope.

Results

Participant characteristics

A total of 81 professionals or volunteers involved in ICDs support completed the background questionnaire. The filter question excluded 6 participants who reported not assessing the needs of ICDs. Based on respondents’ description of their needs’ assessment practices, we excluded 7 additional participants as they focused predominantly on the PwD without assessing the needs of the ICD[1] (n=6) or the assessment of the needs of ICDs had been conducted exclusively in the context of an academic dissertation (n=1). Thirteen other participants did not complete the survey, so the final sample comprised 55 persons.

Participants’ characteristics are presented in Table 1. Most of them were French-speaking (87.3%) and were women (78.2%), with a median age of 47 years. On average, these professionals or volunteers had been in contact with ICDs for 8 years, meeting around 10 of them per year. Eleven professions were represented in the sample, with a majority of nursing staff (i.e. nurses and care assistants) and social workers. Most participants were active in healthcare and/or social institutions (61.8%), as well as in large associations (23.6%), while 5 participants were self-employed.

<p>| Table 1. Participant background characteristics (N=55) |</p>
<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>%</th>
<th>Range</th>
<th>Median (Q1, Q3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Language</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>French</td>
<td>48</td>
<td>87.3%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>German</td>
<td>7</td>
<td>12.7%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>43</td>
<td>78.2%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>11</td>
<td>20.0%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>non-binary</td>
<td>1</td>
<td>1.8%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age (year)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>23-74</td>
<td>47 (35, 57)</td>
</tr>
<tr>
<td>how many (per year)</td>
<td>1-110</td>
<td></td>
<td></td>
<td>10 (4.5, 25)</td>
</tr>
<tr>
<td>missing</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>how long (years)</td>
<td>2-35</td>
<td></td>
<td></td>
<td>8 (5, 20)</td>
</tr>
<tr>
<td>in which position</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nursing staff (i.e. nurses and care assistants)</td>
<td>26</td>
<td>47.3%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social worker</td>
<td>16</td>
<td>29.1%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neuropsychologist</td>
<td>3</td>
<td>5.5%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Volunteer</td>
<td>2</td>
<td>3.6%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>General practitioner</td>
<td>2</td>
<td>3.6%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>1</td>
<td>1.8%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Geriatrician</td>
<td>1</td>
<td>1.8%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pharmacist</td>
<td>1</td>
<td>1.8%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>1</td>
<td>1.8%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychologist</td>
<td>1</td>
<td>1.8%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spiritual care worker</td>
<td>1</td>
<td>1.8%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>through which organisation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health-social institution</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Homecare service (incl. health-social network coordination centre)</td>
<td>19</td>
<td>34.5%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Current practices to assess the needs of ICDs

Description of current assessment practices

Descriptions of current assessment practices were provided in response to question 1, with additional information sometimes given in response to question 2. This led us to code this material jointly into three exclusive categories based on the most systematic component described[2].

The first assessment practice, which was the most widely used (61.8%, n=34), was non-systematic. Participants reported discussing with ICDs, observing them and/or asking them questions, as illustrated by the following quote: *I ask questions to check that there is no overload. If there is an overload, I will try to find solutions (day care, administrative support, etc.) to relieve the person. I also take the time to talk.*

The second assessment practice used a systematic procedure to evaluate the functional limitations of the PwD while concurrently investigating some needs of the ICDs with a non-systematic procedure. Such a practice was described by 6 participants (10.9%), which assessed the level of dependency of the PwD with three types of questionnaires: an Activities of Daily Living (ADL) or an Instrumental Activities of Daily Living (IADL) questionnaire[3] (n=3), and/or the Home-Care Resident Assessment Instrument Minimum Data Set (RAI-HC/MDS) evaluation[4] (n=2) and/or an application form for the request of some kind of financial support (n=2)[5]. The following quote provides an example of this assessment practice: *I
therefore use the standard "disability allowance questionnaire" as a ‘tool’ to carry out prevention and health promotion with the informal caregiver. [...] This tool assesses the need for support of the disabled person, support which is provided by the informal caregiver. [...] The assistance needs to be in the area of personal care such as dressing, toileting, mobilisation, feeding, elimination management, emotional support, communication, autonomy, memory... ID 22

The third assessment practice was reported by one-quarter of the participants (27.3%, n=15) who declared that they used systematic tools to evaluate the needs. Nine respondents used self-developed tools, for which only one provided additional information: [I assess the needs] by asking questions about the various activities that the caregiver does on a daily basis. I use a personal rating (from 1 to 10 like the VAS [Visual Analogue Scale] for pain): on a score of 1 to 10 how exhausted are you to help Mr. or Mrs. in this task. From 4 onwards, I try to understand the reason for the exhaustion and look for a solution with the caregiver. ID 139 The six other participants used the Zarit Burden Interview[6] (n=4) and/or ELADEB[7] scale (n=2) and/or Virginia Henderson Questionnaire[8] (n=1). Although these tools focus on the informal caregiver, the most used of them do not address needs, and none of them provides a specific assessment of the needs of ICDs.

Use of a systematic procedure

When asked if they used a systematic procedure to assess the needs of ICDs, 69.1% of the participants said “no”. However, we observed a discrepancy between these answers and the descriptions given by the participants (see Table 2): While the majority of those answering “no” described using a non-systematic procedure (56.4% of all participants, n=31), seven (12.7%) explained that they systematically used some kind of assessment tool. Conversely, among those answering “yes”, only 8 (14.5% of all participants) actually described a systematic procedure.

Table 2. Use of systematic procedure: participant responses versus identified procedures in the descriptions (N=55)

<table>
<thead>
<tr>
<th>Use of systematic procedure</th>
<th>No</th>
<th>%</th>
<th>Yes</th>
<th>%</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>non-systematic procedure</td>
<td>29</td>
<td>52.7%</td>
<td>5</td>
<td>9.1%</td>
<td>34</td>
<td>61.8%</td>
</tr>
<tr>
<td>systematic assessment focused on PwD but non-systematic for ICD</td>
<td>2</td>
<td>3.6%</td>
<td>4</td>
<td>7.3%</td>
<td>6</td>
<td>10.9%</td>
</tr>
<tr>
<td>systematic procedure</td>
<td>7</td>
<td>12.7%</td>
<td>8</td>
<td>14.5%</td>
<td>15</td>
<td>27.3%</td>
</tr>
<tr>
<td>Total</td>
<td>38</td>
<td>69.1%</td>
<td>17</td>
<td>30.9%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Consistency of practices within the organisation
More than half of the participants (58.2%, n=32) reported homogenous needs assessment practices within their organisation, yet a large proportion of respondents (41.8%, n=23) considered that their colleagues assessed the needs of ICDs in heterogenous ways. Among them, 73.9% (n=17) described that each person assessed these needs differently, while 17.4% (n=4) reported differences between departments or professions. Differences were explained by the highly individualized nature of the procedure (n=7), the lack of a common tool to assess needs (n=7), or a different use of common tools (n=3). One person did not answer this question.

*We do not have a specific tool or procedure for assessing the needs of informal caregivers in our organisation. So, each social worker assesses the needs differently.* ID 21

Training in needs assessment

Nearly half of the respondents (n=26, 47.3%) claimed to be trained to assess needs. Among these, 10 cited a specialised continuing education programme (e.g. in psychogeriatrics), 7 mentioned training related to the use of a specific tool or method (e.g. RAI or ELADEB), 3 cited their primary professional training (e.g. as a psychologist or a nurse), 3 referred to a short course provided by associations as a preparation for volunteer work with PwD, and one mentioned internal training by colleagues. Two descriptions could not be classified in the above categories as they were too vague.

Average duration of a needs’ assessment

The amount of time invested to assess the needs of ICDs ranged from 5 minutes to 2 hours, with a median of 45 min (Q1=17.5, Q3=75, n=49). A quarter of all respondents (24.5%, n=12) used 15 minutes or less.

Frequency of reassessment

Eighty percent (n=44) of the participants claimed to reassess the needs of ICDs. Regular reassessment was the most common (61.4%, n=37), although the frequency was highly variable (range from “weekly or more if needed” to “once a year”) or not quantifiable (e.g. “at each visit” or “after two sessions”). One quarter reported irregular reassessment (22.7%, n=10), as exemplified in this answer: *at each appointment, the frequency of the appointments depends on the patient’s situation* ID 31. The others (15.9%, n=7) mentioned reassessing non-systematically or only when they had follow-up contacts with the ICDs, as expressed here: *I only reassess if I have contact with the person again. So, there is no usual time after which a needs assessment is carried out. This is because we have mostly one-off requests from our clients.* ID 21.

Feedback given to ICDs about their needs

The vast majority of participants (86.5%, n=45) answered that they gave feedback to the ICDs after assessing their needs, while only 13.5% (n=7) provided no feedback (*missing n=3*). Descriptions of the content of each feedback (n=28) showed that 78.6% (n=22) gave advice or offered help, 50% (n=14)
reformulated or acknowledged the needs, and 21.4% (n=6) referred the person to other support services. Additional details provided by some participants suggested that feedback was mainly provided orally (n=22 out of 30; written n=6, oral and written n=2) and at the moment (n=11 out of 14; a posteriori n=3). The following example is a feedback with advice and validation, as well as referral to the appropriate services: During the interview, I give them hints depending on their specific needs. I refer them to competent services when this is beyond my skills. I do not give them formal feedback. [...] The feedback consists mainly of intervention tips and also of listening and recognizing their investment, the resulting fatigue, the importance of not forgetting themselves in order to be able to continue caring. ID 26

Transmission of the collected information

Two thirds of the respondents said that they passed on the information collected about the needs of ICDs to other professionals (64.2%, n=34; no transmission 35.8%, n=19; missing n=2). Over half (55.9%, n=19) mentioned active internal transmission, often to inform colleagues involved in care, as in this example: In part, to the healthcare assistants who work in our respite care service: this mainly concerns the situation and information about the patient they are going to take care of. For the needs of the relatives, mainly to our home counselling volunteers. ID 29

A significant majority explained that they transmitted information to other partners or institutions involved in care (55.9%, n=19), predominantly general practitioners or home care services:

If necessary, this information is shared (verbally or in writing) with our network partners when implementing the support service. ID 72 Among these responses, 7 said they did both types of transmission, as in this example: We do transmissions to our nursing colleagues and also to the physicians, the liaison service if necessary, and we also work with [the palliative home care team] to find out how it is going at home. ID 174

Several responses mentioned transmission to family members, without specifying whether the information concerned the needs of the ICD or of the PwD (20.6%, n=7). Among the responses which specified the mode of transmission (n=20), written transmission was the most common (n=10; oral and written n=5; oral n=5).

Storage of the collected information

Almost all respondents said that the information collected about the needs of ICDs was stored (90.9%, n=50; not stored anywhere n=5). Storage was predominantly done in some form of patient or client file (68%, n=34), and sometimes in a file linked to an assessment tool (12%, n=6). The collected data were often stored in the PwD’s file (57.9%, n=22 out of 38; ICD’s file n=8; unclear n=8). Other storage practices included unspecified reports or computer programs (14%, n=7) and personal notes (10%, n=5). Among the responses which specified the storage support (n=29), a vast majority indicated computer storage (89.7%, n=26, out of which 3 with paper backup; paper only n=3).
Access to the stored information

Among participants reporting that they shared their stored data (n=40, missing n=5), 82.5% (n=33) said that these could be accessed by all their colleagues, i.e. their whole team, department or institution; six also explicitly mentioned here their hierarchy. Six participants (15%) responded that access was limited to specific stakeholders, half of them mentioning that these stakeholders need to be involved in care: My colleagues who may be asked to replace me in case of emergency or absence ID 72. One person described that the data was only accessible by the organisation's management team (2.5%).

[1] Examples of responses:

The close family has given me several suggestions for care, and observation of the person [with dementia] and their living environment helps me to make the right choices. [...] ID 47

In my situation, the person suffering from Alzheimer's lives alone, and the informal caregivers mainly come forward by telephone [...]. I observe 'taboo', minimization, and unfortunately even indifference on the part of some family members. ID 87

[2] For example, descriptions of using a questionnaire and also discussing with the ICD were coded as “using systematic tools to evaluate the needs of ICDs”.

[3] Activities of daily living (ADL) is a questionnaire to assess the level of dependence for essential activities such as feeding, bathing or moving around, while Instrumental activities of daily living (IADL) is a questionnaire to assess the level of dependence for functional activities like shopping, cooking or housekeeping [29].

[4] Resident Assessment Instrument – Home-Care (RAI-HC) / Minimum Data Set (MDS) is a standardized tool for clinical analysis and targeted intervention plans. It covers 19 domains such as cognitive status, nutritional status and hydration, as well as social function and support from family and friends [30]. The latter is limited to three questions asking about the existence of caregivers, whether they can continue to help, and some information about the help given.

[5] Short questionnaire based on ADL/IADL to assess the level of dependence of the PwD.

[6] The Zarit Burden Interview assesses the subjective burden of informal caregiver focusing on the impressions and feelings most frequently experienced by the ICD such as feelings associated with the PwD’s care, health, sense of responsibility, relationships with other family members [31].

[7] The Lausanne ELADEB scales allow assessment of psychiatric patients' difficulties and needs in 18 domains covering pragmatic aspects of daily life (e.g. finances, free time, household maintenance), relational life and social network (e.g. family or sentimental relationships) and the health sphere (e.g. nutrition, personal hygiene or psychological state) [32].

[8] The Virginia Henderson Questionnaire defines 14 components required for effective nursing care, based on human needs (e.g. sleep and rest, avoiding dangers, or acting on beliefs and values) [33].

Discussion
This study aimed to describe current evaluation practices in one Swiss canton, to identify strengths and weaknesses. In terms of strengths, the results indicate that a large number of professionals and volunteers with diverse professional backgrounds and institutional affiliations assessed the needs of ICDs. They used 45 minutes on average, although one quarter used 15 minutes or less. Eighty percent reassessed the needs of ICDs, in most cases on a regular basis, varying from “weekly or less” to “once a year”, and 86.5% claimed to give feedback to ICDs: giving advice or offering help, rephrasing or acknowledging, or referring to other support services.

In terms of weaknesses, only one quarter of the professionals and volunteers proceeded in a systematic way with a focus on the ICD; the tools they used mostly focused on aspects of family care other than needs (e.g. burden), or were home-made and unvalidated. The other respondents predominantly used non-systematic procedures (62%) or relied on systematic tools focusing on the PwD (11%). Nearly half of the participants said that ICDs’ needs assessment was not conducted in a consistent way within their organization, and only half of the participants (47.3%) reported being trained for such an assessment. These findings can be explained at least in part by the lack of clinically-relevant validated tools for ICDs’ needs assessment [34], which is even more pronounced in French or German than in English [35]. A common validated tool would likely increase assessment efficiency and facilitate coordination through the use of a shared knowledge base. The collected information was usually stored in the organisation’s files - predominantly in the PwD’s file - and transmitted to colleagues involved in the situation or to members of the network.

**Impact on the efficiency of the network to support ICDs**

The diversity of assessment practices reflects the struggles of the healthcare system to provide support services based on the needs of ICDs. While each provider considers assessing the needs of ICDs and mobilizes significant resources to do so, the predominant approaches described seem to miss their core target. Indeed, although non-systematic assessments can provide attention, empathy and understanding to ICDs, who are sensitive to it [36], they do not proactively and effectively help ICDs to identify their needs, while this is a very common challenge in this population [14]. The main risks of a non-systematic procedure are that the provider will identify only the needs of which the ICD is already aware, or those which are the most relevant to the provider, leaving other important needs unnoticed and unattended until revealed by a crisis situation. Assessments that focus on the needs of PwDs run the risk of leaving ICDs in the background, limiting them to their instrumental role and failing to recognize them as individuals [37]. While an ICD status cannot exist without the presence of a PwD, the needs of ICDs are not limited to their instrumental role (e.g. being able to provide the required support to the PwD) but encompass much broader issues, such as social needs to maintain their sense of belonging to the community, emotional needs to face the losses and changes in the relationship, or spiritual needs to make sense of the situation. In addition, assessments that emphasize the needs of PwDs reinforce the common tendency of ICDs to neglect their needs as they focus predominantly on those of the PwD. Indeed, some ICDs report feeling instrumentalized due to a lack of interest for their individual needs, which in turn reduces the quality and adequacy of the support or information they receive [36]. The systematic assessment
practices focused on ICDs described by the providers also risk missing their target as they assess aspects other than needs, are not specific to ICDs or use tools which are not scientifically validated. While needs identification is the keystone of an effective support system [38], none of the current assessment practices seem to provide a global overview of the needs of the ICDs.

The diversity of practices does not support an efficient flow of information about the needs of ICDs, which makes communication and coordination within the network of ICD support providers more complex, risking fragmentation. This situation places a heavy burden on the ICDs, who have to proactively identify their needs, make multiple requests and explain their situation each time in order to obtain support.

**Implications for practice**

First, our results underscore the importance of developing a questionnaire usable by diverse providers to assess the needs of ICDs extensively and efficiently, with a specific focus on the ICD. This would foster a person-centred approach with ICDs, would enable consistency of practices within organisations and more efficient communication between the different service providers. Such a questionnaire has been developed by members of our team, by selecting a set of items documenting the diversity of the needs of ICDs from existing questionnaires with a good content validity [36]. Another questionnaire was recently developed in England, using items generated by ICDs, and has been showed to have good psychometric properties [39]; however this questionnaire primarily measures quality of life in ICDs, and only secondarily unmet needs, which can lead to a confusion between these concepts.

Secondly, a broader approach is required concerning the storage and transmission of such information in accordance with the Swiss Data Protection Act, or its equivalents in other countries. Currently, information about the needs of the ICD is scattered between organisations and often stored in the PwD’s file, limiting the possibility to gain an overview in order to effectively plan ICDs’ support. How to centralize and enable the transmission of the data to the right stakeholders remains an open question. These issues are closely related to those around the electronic healthcare record. Even if the ethical, legal and technical developments and the considerations formulated in this context [e.g. 40] can be used as a reference point, they will require adaptions to the specific context of informal caregiving. Our results have underlined that this context raises specific strategic questions such as 1) how can the healthcare system identify the (usually healthy) ICD as a “patient” with individual needs which are largely different from those of the PwD; 2) how can the health and social sectors become more interconnected to jointly address the complex needs of ICDs. These challenges need to be addressed with a strategic policy regarding the recognition of informal caregivers across the social and healthcare systems.

Third, the current shortage of healthcare professionals [41] and the wish for autonomy of many ICDs [42] raise the question of providing direct access to such a questionnaire for ICDs interested in self-assessing their needs, supporting their empowerment. This could be done through a dedicated online platform allowing ICDs to evaluate their needs, including their evolution over time, as well as to send their results to diverse providers and/or to contact the local informal caregivers’ helpline for referral.
Strengths and limitations

Given the scarce literature available on the topic, this study was exploratory and primarily aimed at investigating a variety of aspects related to the assessment of the needs of ICDs, which precluded in-depth examinations. It nevertheless shed light on some topics warranting deeper investigation, such as data protection management or the types of needs assessed by the different healthcare professionals, in order to determine more precisely the amount of exhaustivity and overlap in the current practices regarding ICDs’ needs evaluation. Another limitation is our small number of participants in most occupations, which prevented us from conducting subgroup analyses, but allowed us to achieve high diversity within our sample reflecting the numerous types of professionals and organisations providing support for ICDs. A third limitation is our focus on a single canton in Switzerland, which limits the generalization of our findings.

The main strength of this study is the diversity of its sample including 11 occupations and 12 types of organisations, covering most of the profiles of persons involved in the assessment of needs of ICDs and thereby providing an informative picture of their current practices.

Conclusions

Our study provides concrete examples of how current practices of support providers in assessing the needs of ICDs maintain well-documented problems: The fragmentation of the network offering support for ICDs with poor coordination between the diverse providers and the long and winding trajectory of ICDs to find support options meeting their needs. The absence of a targeted, systematic and common tool for the assessment of ICDs’ needs was identified as a core barrier. As a first step towards improving these problems, providers should thus rely on a tool that is 1) clinically relevant and facilitating efficient referral, i.e. that provides an overview of needs and simultaneously allows for a fine-tuned detection of the specific needs of each ICD, and 2) cross-professional, i.e. which is relevant for the diverse providers involved in supporting ICDs and can therefore facilitate communication and coordination among them.

List Of Abbreviations

ICD   Informal Caregiver of a person with Dementia

PwD   Person with Dementia

Declarations

Ethics approval and consent to participate

The project protocol was submitted to the official local ethics review board (Commission cantonale d’éthique de la recherche sur l’être humain du canton de Vaud, CER-VD; request REQ-2017-00315), which
declared that the project does not fall under the Swiss federal law on research on human beings and therefore required no authorisation.

All methods were carried out in accordance with relevant guidelines and regulations. All materials were submitted and validated by a panel of senior researchers, and were pre-tested with people who met the inclusion criteria. Informed consent was obtained from all participants in electronic format at the beginning of the survey.

Consent for publication

Not applicable.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

Regarding the study: SP designed and supervised the project and analyses; NP coordinated the project and carried out the data collection and analysis.

Regarding this article: SP wrote the introduction, NP the method and results, and IC-NP the discussion and conclusion. First drafts were enriched and proofread by all the authors, so that all authors contributed substantially to the writing of the manuscript and have read and approved the final version.

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**Supplementary Files**

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