

THEME 4 – Informal care

1. INTRODUCTION – definition, relevance

1.1 Definition of 'Informal care' and relevance for the TRIADÉ project.

Informal care means various types of care that are not provided on a professional basis; it enhances family care as well as voluntary care.

Family caregiving (Dutch: 'mantelzorg' and English: 'informal care') is defined by the Netherlands Ministry of Health as "the long-term care for a person in need of help that is provided by people from that person's immediate environment and which is not provided within the framework of a caring profession, in which the care provision directly arises from the relevant social relationship" (VWS, 2001). Family caregivers do not always think of themselves as caregivers. This is true, for example, of parents of handicapped children, partners who care for each other more than the average couple do and people from other ethnic or cultural backgrounds. They rather view the care that they are giving as 'usual care', although it can be very intensive, especially when the disabled person lives at home. When there is no professional support involved, that makes it hard to reach out to these people to support them.

Voluntary care is care provided on a non-mandatory and unpaid basis to people in need of help outside one's own social network, whether or not as a supplement to professional care or in order to support or replace carers (EIZ website, 2005).

Support services for informal caregivers vary considerably throughout Europe (Monika Riedel and Martin Kraus¹). In many European countries such services had not received much attention until recently. In recent years however, this notion has changed and the need for public support of informal caregivers has been placed on the social policy agenda in several countries. The underlying reasons for this are simple but pressing: 'vergrijzing' an aging population, rising care costs and the anticipated labour shortages are necessitating cost control measures and other interventions in the care system.

The contribution of volunteers (students, retired people, unemployed) in the health care sector is a relatively new concept in most countries. Supporting elderly people and vulnerable locals and people with a small social network through the help of a volunteer is considered a very interesting concept and what is needed to stimulate and facilitate this should be considered.

¹ Informal Care Provision in Europe: regulations and profiles of providers, 2011

The fact that support services for family caregivers vary considerably throughout Europe was noticeable in the TRIADÉ project. In the presented best practices in Valencia, Val- de Marne and Rotterdam, the topics were the cooperation between the professionals and the family caregivers and different ways to support the family caregivers.

On the basis of literature and scientific research, the CVD Rotterdam developed 5 key elements of support for family caregivers :

- Information and advice: Practical support , the promotion/representation of their interests
- Education : knowledge of the disease and the restrictions and handicaps, implication on behavioural changes and how to deal with it, managing expectations
- Emotional support /personal care and attention for the family carer
- Respite care and relaxation
- To share experiences

Taking into account these elements is a good way to analyse the needs of a family caregiver.

Family caregivers and the professionals who support them should be aware that taking care of a relative can be intensive and family caregivers can get overloaded. We encourage people to live independently in their own houses as long as they can and to rely on their own network when necessary. The contribution of informal caregivers and volunteers to the care system is increasing and people don't tend to 'give up' on there loved ones. The Caregiver Strain Index (CSI), developed by B. Robinson, 1983 is a common used instrument to measure the strain of informal caregivers. It also gives an indication of stress and the symptoms of an overload and a burn out. In Rotterdam , the estimation is that there are 15.000 overloaded family caregivers! In Rotterdam as well as in Val- de Marne the local government is actively reaching out to support them.

Especially when people live at home, professional caregivers need to cooperate with the family caregivers. The 'Sofa-model' (developed by the Duth center of expertise of family caregiving) offers the main ingredients for the cooperation between the client, the family caregiver and the professional and it structures the various forms of communication and interventions. It is a "practice based" model but is also based on scientific research (Twigg en Atkin uit 1994, 'Carers perceived policy and practice in informal care'). It shows that a family caregiver has different roles and, in the communication and intervention, the professional should be aware of these different roles. The family caregiver can be a partner of the professional in providing the best care for the client, he can be an informant (however sometimes he is a personal en emotional involved informant) and he can be a client (when he is in need of personal care and attention himself). Taking these roles into account the professional needs to cooperate with the informal caregivers and support and facilitate them.

1.2 Informal care - corner stone of an inclusive approach

Relation to the theme Quality of Life

Quality of life is to a considerable degree determined by having meaningful relationships. Family caregivers are part of the social network of the client. Due to this social relationship, informal caregivers are willing to give care and (emotional) support to the client. When the aging client still lives at home the informal care and support can often be intensive. For clients who live in institutions or sheltered homes, informal caregivers are also an important, constant factor in their lives. They often have a long-lasting and intensive emotional bond. Therefore, the informal caregiver contributes in a significant way to the perceived quality of life of the client. For professional caregivers, informal caregivers play an important role. Especially, for clients with cognitive problems, informal caregivers are often 'the voice' and can give a source of information for healthcare professionals, when it comes to the needs, the habits and the historical background of the client. Professional care will improve in quality (and so will the quality of life of the client) if the knowledge and experience of the informal caregivers is taken into account.

As for voluntary caregivers, when there is a good match between the client(s) and the volunteer and the volunteer is well prepared and guided in his voluntary work, it can also contribute to the quality of life of the client. They can carry out a lot of social activities for which professionals have not enough time and can be a good 'equal' buddy or friend for clients with a small social network.

Relation to the theme the new professional and the relationship between formal and informal care

Family caregivers play an important role in the life of the client. Especially when people live at home professional caregivers need to cooperate with the family caregivers. The workload and maybe even the quality of life of the informal caregiver, should be given attention. We encourage people to live independently in their own houses as long as they can and to rely on their own network when necessary. The contribution of informal caregivers and volunteers to the care system is increasing. If the informal caregiver can contribute satisfactorily to the care of the client (in effective coordination with the professional caregivers) he / she will contribute significantly to the quality of life of the client. If an informal caregiver is overloaded, there will be a negative effect on the quality of life of the client. Therefore, it is also the role of the professional to pay attention to the workload and the quality of life of the caregiver and, if necessary, to provide support, or to take over care (temporary). Training and education of professionals to support informal caregivers and to signal overload, should be part of the policy of professional organizations.

2. GOOD PRACTICES – description, critical factors of success

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| GP 1 | Training to target group families (elderly people) and the Community |
| | Presented & discussed : 1nd international TRIADÉ meeting (Valencia, Esp) |
| DESCRIPTION GP | |
| Topics | <ul style="list-style-type: none"> - informal care - cooperation informal care – professional care |
| General objectives | Generalize objectives and bio-psycho-social and functional center actions with families and community regarding dependent elderly person care, in order to improve its life quality and decrease the caregivers stress. |
| Relevance cc. TRIADÉ-project | To detect by our center and community the needs of knowledge, information and actions of informal caregivers regarding the care of dependent elderly people; specifically those who suffer from neurogenerative disorders and deep geriatric symptoms. |
| Summary/description of the practice | <p>The day center interdisciplinary team detects the training and information needs of families and community through different means: Phone calls, Face-to-face interviews, Agendas, Clinical observation during the daily care, a demand from municipality social workers related to family or community needs of training or information, verbal communication from the elderly people social context to improve the general knowledge and information about the dependent early people issue.</p> <p>These needs are collected and classified. Two types of actions addressed to elderly people families are being carried out depending on whether it is considered to train or inform at individual level due to the particular case idiosyncrasy; or it is preferable to do the same by groups, because a specific need is common to several families.</p> <p>The topic to develop focuses on:</p> <ul style="list-style-type: none"> - The neurodegenerative process and its training and information. Action plan of the center. Guidelines to be implemented at home. Management of short/long term evolution. Management of needed procedures to obtain technical helps (support products) and orthopedic materials for the final user. - Modification and adaptation of elderly people home surrounding. - Strategies to stress management - Geriatric syndromes: dysphagia, incontinence, dementia, motionlessness, falls, plurypathology, malnutrition - Fragility (age factor) - Heath enhancement: active ageing, health cares <p>Once the need or demand is settled, the multidisciplinary team determines the topic to address and the professional who are going to take part. One training day is proposed for all these cases and the center prepares the training.</p> <p>Families are called thorough agendas or ordinary mails. The community is called through the municipality or other means such as local newspapers.</p> <p>Once the planned training has been given, a follow-up is carried out to the trained families through phone calls, agendas and as many individual interviews as required.</p> |

| IMPLEMENTATION OF THE PRACTICE | |
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| Target group | Caring families, who usually are the spouses or sons/daughters who have not received either any previous instruction, nor training about degenerative ageing process or/and dementia and problems associated to it. Also groups of non professionals people previously selected by the municipality, who usually are unemployed or people in risk of social exclusion |
| Resources/budget | - Professional time - Physiotherapy, occupational therapy, nursery and psychology materials. - Laptop and projector. Transparencies. - Written materials |
| Evaluation | Follow-up is not carried out in the case of the community. In neither case evaluation is carried out. Just some annual indicators are set up by the center understood as proposal of improving the service quality and a report of developed actions. The action impact on the families is evaluated day by day and registered in al professional follow-up sheets. |
| Transferability | Easy to transfer |

| GP 2 | Taking care together: experience the dialogue |
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| | Presented & discussed : 3rd international TRIADÉ meeting (Rotterdam, NL) |
| DESCRIPTION GP | |
| Topics | - informal care - cooperation informal care – professional care |
| General objectives | Better coordination between formal care (professionals), and informal care (family carers) |
| Relevance cc. TRIADÉ-project | This best practice connects formal and informal care by learning together and from each other. We think this is very important to improve the care for the clients and strengthen the position of the informal caregivers. This GP has been implemented in a nursing home, but can also be applied in different settings. |
| Summary/description of the practice | The care of family and friends does not stop at the front door of the nursing home. Relatives and other members of the client's network are nowadays as much as possible involved in the care of their loved ones. To take care together, professional and informal care, it is important that there is a good dialogue at the work floor between nurses, family members and the client. By keeping in touch with each other, good listening and asking the right questions it's possible to improve the care around the residents. Contacts are more enjoyable and residents feel more at home in the care center. Family members are more willing to lend a hand when the contact with the professionals proceeds pleasantly. A care facility has asked Zorgbelang South Holland to develop a customized workshop for family and professionals together. This concerns in particular the care of psycho-geriatric residents. Most workshops and training sessions in which the dialogue is a central theme, are aimed at professionals: how do I deal with the family? A workshop in which both perspectives (family and professional) are represented, is innovative. |

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| | <p>Based on input from separate group discussions with managers/team leaders, nurses / carers and family members the workshop is developed. Dialogue and progress-focused communication techniques are central items in the workshops.</p> <p>Below you can find the structure of the workshop. It consists of two sessions with the following topics:</p> <ul style="list-style-type: none"> • Participants, professionals and family members, get simple practical guidelines which are widely practiced. • Participants work with their own cases. • Participants practice what they need in practice and get specific feedback. • Coaches have much experience as a trainer, but also in contacts with clients and family members. • Trainers also work as a trainer-actor so that the participants can practice their skills in a safe setting. |
| IMPLEMENTATION OF THE PRACTICE | |
| Target group | Family of residents in nursing homes and professionals |
| Resources/budget | Training folder Roleplay Practical situations Movie about communication Flip over and post its |
| Evaluation | The evaluations showed that the participants have learned very much from each other in the workshop and learned many things which are useful in practice. The workshop can be customized as needed for other care organizations. |
| Transferability | Easy to transfer |

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| GP 3 | Maatjes Vrijwillige Zorg (MVZ) |
| | Presented & discussed : 3rd international TRIADÉ meeting (Rotterdam, NL) |
| DESCRIPTION GP | |
| Topics | - informal care (voluntary care) |
| General objectives | Supporting elderly people and vulnerable locals and people with a small social network through the deployment of a volunteer as a buddy. |
| Relevance cc. TRIADÉ-project | Buddy projects and the help volunteers can give to vulnerable people in Rotterdam is highly developed and of great importance to the city and the welfare of its citizens. MVZ is an example of a well-organized system of volunteers which can be inspirational for the other organizations of the TRIADÉ project. |
| Summary/description of the practice | <p>MVZ is a collaboration of nearly 45 voluntary organizations based in Rotterdam. These organizations offer assistance to Rotterdam residents who need a helping hand, for whatever reason, volunteer assistance in the person of a buddy.</p> <p>A buddy is someone who wants to support another volunteer and give him or her attention for a longer period of time. Buddies visit lonely elderly at home or walk with them and they accompany people to the hospital. A buddy can also do practical things, like going to the store together, but pals also provide homework-assistance to children and help others with their administration and finances.</p> <p>Volunteers want to participate because they find it important to play a part in society. At the same time this care can never be a substitute for the responsibility that people</p> |

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| | <p>have for their own lives. MVZ enables organizations, who organize care for each other and volunteer work, to meet, strengthen and learn from each other so that optimum shape is given to civil society. A society in which everyone participates.</p> <p>Hotline The most important daily activity of MVZ is the settlement of the incoming requests for help. Anyone who has a question can contact the contact point and one of the employees of MVZ helps them.</p> <p>The questions come from relatives or friends and, increasingly, carers and professionals such as social workers, VraagWijzer (an office for information for citizens in Rotterdam) and other members of the community teams, as well as caregivers and physiotherapists.</p> <p>The question is clarified and described, we look at which of the MVZ organizations can accommodate the question. MVZ does not have its own volunteers.</p> <p>Knowledge and experience MVZ is a network where voluntary organizations share knowledge and experience during several meetings in a year. MVZ also organizes activities such as a conference or a buddy market. We try to keep organizations informed of current developments and organize, as necessary, theme-meetings about these developments.</p> <p>Student volunteers MVZ has close contacts with the university of applied sciences, Inholland. First-year students can do their internship in the form of student volunteering at MVZ organizations. Students thus make a first experience in practice and for organizations this is a welcome addition to their volunteer base. Every year more than 300 students are mediated in this way.</p> <p>Education For buddies, family carers and for professional coordinators MVZ organizes workshops, theme-meetings and courses. The topics of the activities are often raised by the MVZ organizations.</p> <p>Culture as a form of appreciation In appreciation of all their efforts volunteers can, along with their buddy, go to concerts and performances with discount. This stems from a collaboration with the Ro Theater, Scapino Ballet, Theater Zuidplein and De Doelen.</p> |
| IMPLEMENTATION OF THE PRACTICE | |
| Target group | Family of residents in nursing homes and professionals |
| Resources/budget | Training folder Role-play Practical situations Movie about communication Flip over and post its |
| Evaluation | The evaluations showed that the participants have learned very much from each other in the workshop and learned many things which are useful in practice. The workshop can be customized as needed for other care organizations. |
| Transferability | Easy to transfer |

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| GP 4 | Informal care in Val-de-Marne |
| | Presented & discussed : 4nd international TRIADÉ meeting (Val-de-Marne, Fr) |
| DESCRIPTION GP | |
| Topics | - informal care |
| General objectives | <ul style="list-style-type: none"> - To support the informal caregivers in their administrative procedures to access to various aids and trainings through coordination of actors from social, elderly and disability fields in Val-de-Marne; - To allow wellbeing of informal caregivers and theirs relatives. |
| Relevance cc. TRIADÉ-project | Following the meeting in Rotterdam which focused on informal care, we considered that it would be appropriate to present, as a part of the departmental policy of support of caregivers (informal and formal), a specific action based on information and exchange between informal and formal caregivers. This action allows to reach as more informal caregivers as we can in order to improve their care, their wellbeing and wellbeing of their cared elderly and disabled people. |
| Summary/description of the practice | <p>Forum of caregivers is an event organized annually by the Departmental Council of Val-de-Marne, in order to gather and to inform informal caregivers on existing devices and aids. Also, the forum allows to identify informal caregivers not registered until today in Val-de-Marne.</p> <p>In France, informal caregivers represent one person out of six. Many of them are unaware that they also have the right to be supported. Caring for a person with reduced autonomy can lead to isolation and exhaustion. The health and well-being of a caregiver are essential to the person who is being cared for.</p> <p>In 2016, a forum for caregivers took place on October 3rd in the museum of Modern Art called MAC VAL allowing caregivers and their cared people to discover this adapted place accessible for everyone. Caregivers could come and participate with their cared relatives.</p> <p>During the whole day, the visitors (informal caregivers) meet professionals at the information points (stands) divided into a following spheres:</p> <ol style="list-style-type: none"> 1. Right: institutions and associations providing information about possible aids that they can benefit; 2. Health: hospitals, pension fund, security associations: all necessary resources to protect health; 3. Home: how to find help you need to live well at home; 4. Institutions: panel of services to support elderly and disabled people; 5. Active together: discussion with organizations that reflect and act to facilitate travel, leisure, meetings, training, etc. <p>All organizations, associations and institutions participating to the forum, through a dynamic animation of their stands, valorise their actions and help informal caregivers to engage necessary steps to meet their needs (fulfilling shifts, making the appointments...). Two round tables are proposed for a collective exchange between visitors and professionals on two key life issues:</p> <ul style="list-style-type: none"> - Announcement of loss of autonomy: from acceptance to adaptation; - How to hold together every day without feeling guilty? |

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| | <p>Each round table is preceded by a 30 minutes theatre piece inviting visitors (informal caregivers) to share a moment of their life in order to go to the point of the subject and avoid too theoretical discourse.</p> <p>“Theater forum” (style of theatre and debate) is the best way to let visitors to express themselves on stage with a moderation of a professional actor allowing the quality of exchanges and giving them concert answers to their concrete questions/problems that they could have (medical resources, respite, support group, etc.).</p> <p>Visitors can also discover various day activities available in workshops for caregivers and their cared people:</p> <ol style="list-style-type: none"> 1. Workshops for all: adapted visits of the museum Mac Val, relaxation and music therapy, soft gym, good gestures of daily life, initiation on digital devices, workshops organized by Maison départementale pour personnes handicapées, workshop of how to adapt a home of elderly or disabled people. 2. Workshops dedicated to elderly and disabled people came with their caregivers: realization of a fresco with Mutual Self help Group of the municipality of Vitry sur Seine. <p>A practical guide (brochure) has been made and given to caregivers gathering important information and resources for caregivers.</p> |
| IMPLEMENTATION OF THE PRACTICE | |
| Target group | Informal caregivers; Formal caregivers; Elderly and disabled people; |
| Resources/budget | Material and logistical resources. |
| Evaluation | Nearly 400 people came in Mac Val on 3th of October and hundreds of partners were mobilized to keep the stands, animate workshops, speak at round ables. |
| Transferability | |

3. CONCLUSIONS & RECOMMENDATIONS

Main elements; to discuss in Sweden:

Conclusion: Family caregivers are increasingly important in today’s society. It is important to facilitate and support them.

- Development of services to facilitate and support family caregivers (on individual and institutional level and the level of government /policy:
 How to find them?
 How to support them?
 How to relieve them?
- The integration and cooperation of professional care and informal care

Conclusion: The contribution of volunteers and the development of services to facilitate and support voluntary caregivers offers opportunities to enlarge the quality of life of disabled people and contributes to a inclusive society

| | Contributing factors | Barriers | Overall discussions, remarks,... |
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| Individual level | | | |
| Institutional level | | | |
| Inter-institutional level | | | |
| Level of government | | | |
| (Education) | | | |