Flanders
State of
the Art

What do we (not) know about informal help in Flanders?

A proposal for closing statistical and knowledge gaps

DEPARTMENT OF
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1 INTRODUCTION

Informal help can be broadly defined as any care and support which is provided by non-professionals and is not compensated as paid employment. In Flanders [1], informal help encompasses several traditional forms, like the customary care which family members provide to each other, self-care, informal care , foster care or care provided by volunteers who are active in care organisations. New types of care are arising as well, such as care volunteers who are active outside of organisations, befriending activities and neighbourhood care. All these types share a few characteristics, namely social and/or spatial proximity, an orientation towards care rather than treatment and the intention to promote physical, mental and social health. Some definitions state that the care must extend beyond what is customary (be exclusive of customary care)[2].

In addition to informal help, Flanders has a well-established sector of formal healthcare and welfare facilities which largely employ professional care workers. The relationship between informal help and formal care, the so-called welfare mix, has changed over the past decades. Partially owing to social and demographic changes, increased weight is being attached to informal help from a policy point of view. The 'socialisation of care' takes centre stage. This is a shift in care which seeks to enable people with (physical, psychological or mental) disabilities, chronically ill people and vulnerable elderly people, with all their abilities and vulnerabilities, to secure their own meaningful place in society, and to support them in this process as and where necessary.

The growing policy attention to informal help is apparent from initiatives in various policy areas (welfare, public health, care, living, work, education and training, etc.) and touches on several policy levels (local, Flemish, federal). In this respect we could say that 'informal help is in all policies'. One of the main policy initiatives was the development of the first Flemish plan on informal care which groups over 100 policy actions into five action pillars: the recognition and acknowledgement of carers, research, information and support, detection and intervention. In terms of research, this policy plan wants priorities to be set for initiating further longitudinal research and/or repetitive living condition research into informal care in Flanders, as well as 'specific research into target groups which have so far remained underaddressed, such as carers of foreign origin and the oldest group of carers'. For young carers the feasibility of a mixed method study should be examined, which involves a combination of quantitative and qualitative research methods (Vandeurzen, 2017).

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1 Flanders also called the Flemish Region is one of the three official regions of Belgium alongside the Walloon Region and the Brussels-Capital Region.

[2] *In Flanders 'informele hulp' (informal help) and 'informele zorg' (informal care) are both used to indicate the different forms of help and caregiving by non-professionals. In this paper we used the term 'informal help' to name those different groups while the term 'informal care' is used for what we call 'mantelzorg' in Flanders, namely: Any care provided on the basis of an existing social relationship (e.g. by a household or family member, an acquaintance or a neighbour) to one or more persons requiring care due to (long-term) illness, disability or old age. Care provided in a professional context and volunteer work do not fall within this scope. "Mantelzorgers" are people who provide "mantelzorg". Further on in this text they are referred to as '(informal) carers'.*

2 RESEARCH QUESTIONS

To answer these research actions from the Flemish plan on informal care, an exploratory study of the knowledge and knowledge gaps regarding informal help was set up. This paper contains the main results of the exploratory study published in a report in Dutch (Bronselaer, Demeyer, Vandezande, Vanden Boer, 2018). This study concentrates on three key questions. First of all, what data are required for a qualitative and reliable monitoring of informal help in Flanders? Secondly, which sources already contain information about informal help in Flanders and which knowledge gaps can be identified? Thirdly, how can identified gaps, if any, be closed? When answering the research questions, two types of informal help are discussed, namely informal care and care volunteers. This focus mainly had a pragmatic reason, namely that not all types of informal help could be researched within the time frame of this study.

3 RESEARCH METHODS

We applied various methods to answer the research questions.
First, we developed a reference framework which delineates the key knowledge that is needed about informal help. To that end, three main knowledge questions were formulated from a policy point of view:

1. Who provides informal help or is willing to do so, and what are the influencing factors?
2. What are the implications and outcome characteristics of informal help and by which factors are they both influenced?
3. Which changes in the provision of informal help or the willingness to do so, in the implications and outcome characteristics and in the factors respond to these three components?

Finding an answer to these knowledge questions is considered to be essential in a policy context in which growing attention is paid to informal help.

Secondly, the knowledge needs were verified against the available knowledge and statistics relating to informal help. For this purpose, we inventoried and analysed Flemish research literature and primary data sources on carers and care volunteers between 2005 and 2017. As far as the research literature was concerned, both qualitative and quantitative studies were mapped. Master theses and opinion-based literature were not considered. As for the primary data sources, data sources which are being used in research were focused on and repetitive data sources were studied in greater detail. Administrative data sources were mostly left out of consideration, since their use in research is limited.

Finally, the self-formulated knowledge needs (see the three key knowledge questions), the available knowledge and the identified knowledge gaps regarding carers and care volunteers were reviewed by Flemish experts during 17 expert interviews. The discussions with the experts were also used to outline four tracks for closing the identified knowledge gaps.

4 MAIN RESULTS

4.1 CARERS AND CARE VOLUNTEERS: TWO SEPARATE GROUPS

In this study informal care is understood to mean ‘Any care provided on the basis of an existing social relationship (e.g. by a household or family member, an acquaintance or a neighbour) to one or more persons requiring care due to (long-term) illness, disability or old age. Care provided in a professional context and volunteer work do not fall within this scope’. In Flemish research, occasional carers are often regarded as informal carers, which is why we do not exclude them from this definition. A care volunteer is understood to mean someone who ‘provides care to one or more persons requiring care due to (long-term) illness, disability or old age, but not on the basis of an existing social relationship (e.g. as volunteer within a care organisation). Care provided in a professional context does not fall within this scope’. The description also includes volunteers who are active outside of organisations or on an occasional basis.

The consulted experts confirmed the importance of distinguishing between these two groups. Not just their profile, but the care context and the implications and outcome of the provided care as well are mostly different in both groups. Several criteria allow us to approach carers and care volunteers as two separate groups: the existence of a social relationship prior to the care or the fact whether or not the care is provided in an organised context. At the same time, several experts draw attention to the grey area in the informal help landscape and the many new types of care which cannot always be reduced to one of these two groups or categories. In both groups, the focus on the specific stage of life is important. It is assumed that a limited number of children and young people in Flanders are engaged as care volunteers, but that there is a relatively substantial group of young carers. The reason for providing care, the nature of the provided care and the implications and outcome of the provided care may differ according to the stage of life the person is at. For children and young people, there are important implications for their education and development, whereas for working-age people the implications for paid employment, for instance, are of greater importance. Within the group of care volunteers, the distinction between working in an organised or non-organised context is also relevant. Several other types of informal help exist as well, such as the customary care which family members provide to each other and self-care. These types are insufficiently covered by the description of ‘carer’ and ‘care volunteer’.

4.2 KNOWLEDGE NEEDS REGARDING CARERS AND CARE VOLUNTEERS

With regard to the needs for scientific knowledge about informal help, from a policy point of view, the consulted experts confirm the importance of the three key knowledge questions. The reason for providing informal help and the willingness to do so, the implications and outcome characteristics and the changes in informal help are regarded as key knowledge needs. As for carers it is emphasised to also include a positive angle and the perspective of the care recipient. On the one hand, similar knowledge needs exist for care volunteers and carers in terms of commitment, availability, willingness, support needs, outcomes, recruitment. On the other hand, there are specific knowledge needs for care volunteers, such as attention to various types or grey zones of volunteer work, professional support or the role of organisations in which care volunteers are active. Finally, the experts also highlight the importance of coordination and cooperation between the different types of informal help on the one hand and with formal care on the other. Support from the social network and contacts with fellow carers must be taken into account as well.

4.3 KNOWLEDGE (GAPS) REGARDING CARERS AND CARE VOLUNTEERS

The analysis of both research literature and primary data sources has revealed that little scientific knowledge and few statistics are available on Flemish care volunteers. These findings were confirmed during the expert interviews. Although some survey sources focus on the large group of volunteers or older volunteers, it is unclear whether these findings are also valid for care volunteers. A number of administrative databases are also in place which contain a limited amount of statistics on volunteers in certain care sectors, such as sitters. However, these statistics do not offer any answers to the three key knowledge questions and do probably not apply to care volunteers from other sectors. Several qualitative studies have also been carried out into new types of care volunteers, such as befriending or neighbourhood care.

Flanders has a richer tradition in researching carers than care volunteers. This shows from the larger number of studies, the research carried out among various sub-groups of carers and the research on various themes. Although Flemish research literature addresses a large number of themes, this does not mean that insights are available into these various themes for all care groups or carers at the different stages of life. Still, in certain cases this is neither necessary nor relevant. One striking element is that no (incl. young or young adult carers, carers of persons who are staying at a residential facility, former carers) or hardly (incl. carers of foreign origin, older carers or working carers) any statistics are available about some care groups. Moreover, it seems that particular themes are not addressed at all in research or only to a limited extent, such as the quality of care, the compensation for and costs of informal care, the sharing of informal care with others, the functioning of informal care networks, the positive experiences or competencies acquired through informal care and the application thereof in other areas of life, the combination and implications of caregiving for paid employment and for the education of young carers or for their entry on the labour market. The altruistic potential for providing informal care among the Flemish population is also discussed only to a limited degree in research literature.

From a methodological point of view it seems that limited research was carried out into the perspective on informal care of the person requiring care. Although some studies discuss the dyadic relationship between the carer and the person requiring care, we did not find any multi-actor studies which approach informal care situations from a network perspective. Moreover, hardly any longitudinal or trend studies were found. Insights are lacking into important long-term trends in informal care, such as the care potential of the Flemish population, the prevalence of informal care in the Flemish population, the objective characteristics of informal care situations, the spread of informal care among potential carers or the implications and outcome characteristics. Finally, no comparative geographical research is available on informal care at the local level. Besides, only occasional attention was paid to research which considers informal care in Flanders from an international comparative perspective.

4.4 THE POTENTIAL OF PRIMARY DATA FOR MONITORING INFORMAL HELP

In Flanders, no repetitive survey research is available which specifically focuses on ‘informal help’ or certain types thereof. However, we did identify four general population surveys which present opportunities for monitoring informal help in Flanders, i.e. the Health Interview Survey (Scientific Institute of Public Health), the Survey Social-cultural Changes in Flanders (Flanders Statistics Authority), SHARE and the City Monitor (Flanders Statistics Authority). These surveys are interesting to monitor the evolution of informal care in Flanders, but do not teach us anything about care volunteers.[3]

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[3] *More information about these surveys can be found at: https://his.wiv-isp.be/SitePages/Home.aspx, http://www.statistiekvlaanderen.be/survey-scv-survey, http://www.share-project.org, http://stadsmonitor.vlaanderen.be*

Each of these data sources has pros and cons. Some sources have insufficient numbers for certain analyses, impose restrictions in terms of the age of respondents or the geographical coverage of the study, do not allow a distinction to be made between carers and volunteers in care, or contain demarcation questions which are insufficiently sensitive or have an uncertain future. Although this search does not generate a unique recommended monitoring instrument, we can learn some things about informal care in Flanders by continuing to monitor the different sources in the future.

Apart from prevalence several other essential topics are highlighted in each of the four examined surveys, such as the socio-demographic and socio-economic backgrounds of the respondents, which may yield interesting information about the background characteristics of carers in Flanders. In (almost) each case the health and welfare profile and the quality of life are surveyed as well. Since these four surveys are population surveys, the profile of carers can be compared to that of ‘other’ or ‘average’ Flemish people in relation to these characteristics. However, the three key knowledge questions which we put forward cannot be adequately answered by means of these four survey studies. An exhaustive monitoring of informal care, let alone informal help, is therefore impossible within Flanders’ current research landscape.

Finally, we identified a few Flemish surveys (Time Use Survey (VUB), Participation Survey (UGent), Family Survey (Department of Welfare, Public Health and Family) and the Belgian Ageing Studies (VUB)) and international surveys (European Social Survey, Labour Force Survey and Statistics on Income and Living Conditions) which hold potential for the monitoring of informal help, but are as yet unsatisfactory.
The same question on informal help has not yet been included twice, or the question did not meet our definition of carers or care volunteers.

5 CLOSING KNOWLEDGE GAPS

To close the identified knowledge gaps we have developed four tracks. The first track was worked out in greater detail in 2017. The other tracks can be given further concrete form in the future.

5.1 MAKING USE OF EXISTING SURVEYS FOR YOUNG CARERS

The first track concerns young carers. Following a scan of foreign studies, the feasibility was examined of a separate survey study which is specifically devoted to the theme of ‘young carers’. This was done in collaboration with the Department of Education and Training (Government of Flanders). Given the over-surveying of schools and the relatively low prevalence of carers among young people, which is illustrated by foreign studies, it was decided to introduce the theme of young carers in two existing survey studies, namely HBSC & LiSO.

HBSC (Health Behaviour in School Aged Children) is designed to gain a better understanding of health-related attitudes and behaviours in young people and the environment in which they develop. The themes researched in the study are lifestyle (such as nutrition, smoking, alcohol use, drug use, sexuality, physical activity), subjective health and mental health, and the social environment of the young individual (family, school and neighbourhood). For Flanders, it is tried to survey a sample of 1,500 pupils in each school year from the 5th year of primary education to the 6th year of secondary education, on a four-yearly basis (Deforche & Hublet, 2014). Within the ‘Family’ questions cluster the HBSC questionnaire will devote attention to the theme of ‘young carers’ in 2018. On the one hand, a series of questions on ‘young carers’ is included, which is developed by De Roos & De Boer, as is done in several other countries organising HBSC.

These questions make it possible to find out which young people are young carers, which is their relationship to the sick household member and how intensively they provide care. In addition, the Flemish HBSC questionnaire includes another series of questions which inquire after various determinants of informal care (the number of children within the household and the rank of the child within the household), the type of care and help the young people provide, there maturity, the degree to which young people worry about home, their feelings of loneliness and whether there are any general or specific activity restrictions). By adding these questions to HBSC, combined with the other data collected through HBSC, insights can be offered into the prevalence of young carers in Flanders, the determinants of young carers, differences in background characteristics and tasks performed between young people who are young carers or not, differences in well-being and health between children who are young carers or not, and Flanders' position with regard to 'young carers' compared to other countries.

Another possibility which was presented by the Department of Education and Training is to have the theme of 'young carers' dovetail with the ongoing LiSO study which is one of the research lines of the Steunpunt voor Onderwijsonderzoek (SONO, Education Research Centre). The LiSO project aims to map and explain the way in which pupils progress through secondary education. The basic principle is that not only factors at the level of the individual pupil and their home environment are significant, but so are factors at the level of the school, class and teacher. Pupils, their parents, subject teachers, form teachers and the school management team will be surveyed to that end. In a number of cases, the survey will be extended to the entire teaching team. LiSO wants to serve as a source of information for schools and policymakers and offer specific insights into school, class and teacher characteristics which are effective for performance (including Dutch and mathematics) and for non-cognitive outcomes (such as school well-being, commitment and interest).

LiSO can count on the participation of more than 90 schools (grouped into 58 pedagogical units) and more than 8,000 pupils. Most of these LiSO pupils started participating in the research in the first year of secondary education in September 2013. They are all monitored by means of tests and questionnaires, while their parents, teachers and management teams deliver information as well. This monitoring runs until 2020. In this way, the choices they make when leaving secondary education can be mapped as well (https://lisoproject.be).

On 11 December 2017, a partnership agreement was concluded between the Centre for Educational Effectiveness and Evaluation (KU Leuven), the Department of Welfare, Public Health and Family and the Department of Education and Training. Through this agreement it was opted to have the theme of 'young carers' tie in with the ongoing LiSO study in three ways.

A first part of the research consists of including the series of questions on 'young carers' by De Roos & De Boer in the pupil survey which is scheduled to be carried out among pupils in the 5th year of secondary education in May 2018. Given LiSO's longitudinal research design, a question will also be included about how long the chronically ill person is present within the household. By adding these questions to LiSO and linking the answers to existing LiSO data, the connection can be examined, among other things, between child, household, class or school characteristics on the one hand and the provision of informal care to a sick household member on the other. The relationship between 'young carers' and school performance and school well-being can be studied in greater detail as well. Finally, opportunities are available for researching the relationship between 'being a young carer or not' and the experiences of form teachers (expectations, participation, pupil-teacher relationship, care at school).

A second part involves the organisation of an online survey among all children who, as a result of the first research part, are identified as staying with a sick household member and who consent to participate in an online survey. The purpose of this survey is to gain a broader and deeper quantitative picture of the care and living situation as well as the support preferences of 'young carers'.

A third part aims to research the theme more profoundly in a qualitative and highly targeted manner, with the following research targets taking centre stage: gaining a better understanding of the lived daily experience and support preferences of young carers, developing and testing proposals for improvement among young carers, acquiring a better insight into how teachers in general and care teachers and staff of pupil guidance centres in particular deal with this theme and this target group, gaining a better picture of the absence or presence of a relevant school policy, formulating proposals for improvement to achieve a stronger school policy to support young carers, and including a coordination with welfare actors in the proposals for improvement. This qualitative research wants to help underpin the structural support policy for young carers with insights originating from the people who are directly involved (young carers and their parents) on the one hand and professionals working in the school context where these children attend education on the other.

5.2 SETTING UP A NEW SURVEY STUDY

The second track concerns the set-up of a new repetitive survey study into types of informal help among young adults, adults and older Flemish people. Multiple experts subscribe to such a population survey, which allows a more coherent, systematic and integral picture to be gained on informal help in Flanders than is currently the case. More specifically, opportunities are seen for studying the coherence between the different types of informal help, for better mapping the dynamics between care provider and care recipient, for keeping a finger on the pulse of developments within the informal help domain, for having this followed by more targeted practice-oriented and deepening research, and for providing governments and interest groups with adequate information. Differing expectations also exist when setting up such a new initiative, like placing sufficient focus on the combination of roles in the different stages of life and paying attention to the local informal care situation and to different types of informal help and vulnerable groups. In this context special emphasis should be placed, through survey research, on difficult to reach groups, such as elderly people. Given the pros and cons of various survey designs, a repetitive cross-sectional survey seems the most suitable. With an eye to identifying relevant changes in Flemish people and people providing informal help, the same survey can be organised every three to five years.

5.3 RESEARCH INTO UNDERADDRESSED THEMES AND GROUPS

The third track for closing knowledge gaps is to perform research into underaddressed themes and groups. Several experts confirmed that a mixed-method approach can be a practicable option, in particular for groups or themes that are insufficiently addressed in the survey study from track 2. Moreover, qualitative research can attribute a different and more profound meaning to statistical findings. We also find that three themes remain underaddressed in research.

The first theme concerns research into informal care situations from a network perspective.
The perspective of the person requiring care and the different care actors are involved in research within the same informal care situation. Research which starts from the person requiring care as the key actor within a care network and maps the characteristics and perspective of the various (potential) care actors, may offer an innovative approach to the exchange relationships between the actors involved, but also to determinants of intensity of care, the type of care tasks carers assume, the distribution of tasks or the implications and outcome characteristics of informal care.

The second theme relates to the group of young adult carers. It is recommended to devote attention to this group through higher education institutions, by focussing on support needs and instruments. The ongoing Dutch research 'Expertiselab Jonge Mantelzorgers; vergroting van veerkracht' may serve as a source of inspiration.

The third theme has to do with care volunteers who work in an organised context. The question is to what extent a population survey into informal help can sufficiently capture the dynamics between welfare or health organisations on the one hand and volunteers who are active in these organisations on the other. Research which surveys a sample of welfare and health organisations through a management questionnaire and at the same time surveys the perspective of active volunteers, will probably better capture these dynamics. The management questionnaire can then be oriented to the organisational perspective on volunteer work in which the following aspects, for example, may be relevant to map: structural organisational characteristics, the recruitment and selection of volunteers, the provided support and training, the follow-up and the vision on the distribution of tasks. A questionnaire among volunteers can be targeted on the experience(s) of the volunteer within the organisation in which he or she is active.

5.4 MAKING KEY STATISTICS AND KNOWLEDGE ABOUT INFORMAL HELP MORE ACCESSIBLE

The fourth track wants consideration to be given to making key statistics and knowledge about informal help available and more accessible. Key statistics on informal help can be found on plenty of websites, in research reports and brochures and on online publication forums, or are partially hidden in administrative databases or survey sources. Making statistics more accessible and integrating them, e.g. on one single website, can generate important added value. This will not only create integrated statistics, but will also uncover key figure gaps regarding informal help. For the selection of key statistics, informal help can be broadly conceived, which means that, in addition to self-care, occasional care, informal care and care volunteers, foster care can also be addressed, for instance. Within the context of such an initiative, data from primary data sources (survey data or administrative data) can be published in processed form as relevant key statistics on informal help. This can be done by one or more actors who belong to the network of Statistics Flanders. In line with the decree on Flemish public statistics the Government of Flanders adopted a vision memorandum and objectives framework on 1 December 2017, which provide direction to a new approach to the selection, production and dissemination of Flemish public statistics. The informal help domain has a role to play in this as well.

It is also recommended to better open up and organise insights from scientific research. The literature review of this research showed that several studies were performed into support instruments or programmes for carers. Compared to the Netherlands, Flanders is lagging behind as far as the integration of knowledge about the effectiveness rate of social interventions is concerned. A 'database on social interventions' like the Dutch MOVISIE does not yet exist in Flanders, but may prevent researchers or professionals from duplicating work or reinventing the wheel. Such a database describes and organises support interventions and programmes according to their effectiveness.

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