Social support as described by foreign-born persons diagnosed with type 2 diabetes mellitus and living in Sweden.

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Original Research paper

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ABSTRACT

The aim of the present study is to explore and describe the meaning of support, and its impact on the life-situation of foreign-born persons diagnosed with Type 2 diabetes mellitus (DM) living in Sweden in relation to gender, age and duration of disease. Mixed methods were employed on a purposive sample of 34 foreign-born adults, diagnosed with Type 2 diabetes; qualitative data were collected by semi-structured interviews, and quantitative data collected by the Norbeck Social Support Questionnaire (NSSQ).

The meaning of 'support' was described by the participants as concerning medical support, informative support and aiding support to learn to manage diabetes. Support influences the entire life, and the need is related to the severity of diabetes and differences regarding age and gender. Participants scored low on the NSSQ regarding total emotional support, total aid, and total function, and 42% had lost an important relationship during the last year. Marital status had no impact on emotional support but aid gave significant figures.

Medical support with regular follow-up and information is important in obtaining affirmation and aid to learn to manage DM.

Key words: individual perceptions; migrants; mixed methods; social support; Type 2 diabetes mellitus

INTRODUCTION

The concept of social support has rarely been studied within the area of diabetes mellitus (DM)(Hjelm &. Berterö, 2009) and no study has been found focusing on foreign-born persons' own perceptions of its content. Social support is of importance for adherence or compliance with given advice about DM management and influence glycaemic control (Charron-Prochownik, 1991; Eriksson & Rosenqvist, 1993). A clear relation between denial of the disease and limited social support has been shown (Toljamo &.Hentinen, 2001).

The developing diabetes pandemia involves essentially Type 2 DM (IDF , 2008), and those facing the greatest risk of being affected are migrants, minority populations, disadvantaged communities in industrialized countries, and populations of developing countries (Shaw *et al*., 2009). Sweden, like many European countries, has become multicultural due to extensive global migration (Sveriges Officiella Statistik, 2008). Almost 16% of the Swedish population is born abroad and > 200 different nationalities are represented. The migrant population in Sweden is dominated by European labour migrants that voluntarily arrived in the post-war period, and the largest groups of migrants are Finns and former Yugoslavians. In the middle of the 1980s, the migration pattern changed and became dominated by refugees forced to leave their countries due to war and persecution. With the exception of former Yugoslavians, most originate from non-European countries in Latin America, the Middle East, Asia, and Africa. The largest group of non-European refugees comprises persons from Iraq (Sveriges Officiella Staistik, 2008).

Diabetes mellitus is a chronic, progressive disease with micro-and macrovascular complications (affecting eye, kidney, lower extremity, heart) likely to develop over time in relation to glycaemic control (International Diabetes Federation, 2009). DM demands adaptation to a new life-style, and the person is trained to take control of the disease by different self-care measures (International Diabetes Federation, 2009). For migrants, the

acculturation process in the new country acts as an additional stressor demanding further adaptation (Berry, 2005). Immigrants and refugees constitute a particularly vulnerable group of persons depending on their migrational background, with experiences of e.g. breaking-up, violence, torture, war, persecution, but also because of adaptational problems in the new country and because of broken and weak social networks (Hull, 1979; Kirkcaldy *et a*l., 2006). Previous investigations have shown broken and limited social networks among migrants compared to native people, and that these negatively affect health (Sundquist, 1995; Kirkcaldy *et al*., 2006). A theory about social resources forms the basis for social support and social networks (Kahn & Antonucci, 1980; Johnson & Hall, 1988) that comprises an interaction between human beings and can be defined quantitatively and qualitatively (Schaefer *et al*., 1981). The likelihood of positive health outcomes is greater if adequate social support is perceived. Individual differences and demographic variables such as age, sex, and culture influence how much social support is needed and/or available (Norbeck, 1981). An instrument, the Norbeck Social Support Questionnaire (NSSQ), based on these models has been developed (Norbeck, 1981; Norbeck *et al*., 1981; 1983). This measures three subscales of social support: affect (actions causing changes), affirmation (the act of emotional confirmation), and aid (to give assistance). The instrument also measures functional network properties (number, duration, frequency) and recent losses of members in the network. Social support and self-efficacy is claimed to play an important role in self-management of DM (Lanting *et al*., 2008). A comparison of Turkish and Moroccan immigrants and native Dutch diabetic patients, by structured interviews, showed that immigrants had higher levels of HbA1C or poorer glycaemic control and reported higher levels of social support from significant others regarding their DM. Dutch patients reported higher levels of self-efficacy, and were more convinced about their ability to perform certain DM tasks. Self-efficacy was shown to be the most important determinant explaining the differences in glycaemic control

but social support for monitoring of blood glucose proved to be a protective determinant for immigrants' HbA1C level.

In Swedish persons diagnosed with type 2 DM the need for support was considered individual and related to gender, age, and duration of disease (Hjelm & Berterö, 2009).

Aim

This study explored and described the meaning of support, and its impact on the life-situation of foreign-born persons diagnosed with Type 2 DM living in Sweden in relation to gender, age and duration of disease. We qualitatively explored social support/support and relate the findings from the interviews with the quantitatively explored social support scores from NSSQ. The research question is: Do participants' views from interviews and from standardized questionnaires converge or differ?

METHODS

A mixed method descriptive concurrent triangulation design as described by Creswell (2003) was used to achieve the specific aims, to analyse findings from different data sources to identify if they converge or depart. Another reason to employ a mixed methods design is that a combination of quantitative and qualitative methods contributes to a more comprehensive understanding of study outcomes (Teddlie &Tashakkori 2009). In mixed methods, both predetermined (quantitative) and emerging (qualitative) methods are used with closed- and open-ended questions. Quantitative and qualitative data collection is concurrent, happening in one phase in the research study. The data is analyzed with statistical and text analysis/content analysis (Crewell 2003).

Local setting and procedure

In the studied area, when patients are diagnosed they are referred to a hospital-based diabetes clinic for investigations and diabetes education. Subsequent care is delivered in primary health care (PHC) with referral to hospital-based clinics for management of complications related to DM and attendance of diabetes classes.

A purposive sample of foreign-born men and women, ≥ 18 years, diagnosed with Type 2 DM was recruited by staff at a hospital-based diabetes clinic. The clinic served persons with DM managed in PHC and in outpatient clinics at the hospital. Those interested in participating filled in a reply coupon that was forwarded to the researchers, who contacted them to set a time and place for the interview. To cover a range of experiences, persons of different age, duration of DM, and treatment type were chosen in order to better understand the complexity of the concept (Patton, 2002) of social support. The study was approved by the Ethics Committee of the University of Lund, and was carried out in accordance with the Helsinki Declaration and with written informed consent from the participants. Preparations were also made to arrange contact for the participants with a social welfare officer or a diabetes team if they should react in the interview situation, and have a need for such a contact.

Data collection; interviews

The interviews were conducted by a female diabetes specialist nurse who was not involved in either the management of the clients or the diabetes clinic. Semi-structured interviews allowed the participants to guide the content within a frame of questions, and aimed to reach a nuanced and deeper understanding of the meaning and implications of social support (Patton. 2002). An interview-guide developed and tested in a previous study of Swedish-born persons with Type 2 DM was used. Three open-ended questions formed the frame of the interviews

and focused on: the meaning of the concept of support, influence of support on the entire life-situation when having DM, and support needed. The interviews were held outside the clinic in secluded rooms. They lasted between 1 and 1.5 h, and were audio-taped. When needed, an authorized interpreter of the same gender and speaking the same language as the participant was used, and the sequential interpretation technique (word for word) was applied. After the interviews the participants answered the structured questionnaire, NSSQ, which was read by the interviewer and translated by the interpreter, and the participant answered the questions one by one. Data collection always followed this order to avoid any influence on the participants' perceptions of how to describe support.

Data collection; Norbert Social Support Questionnaire (NSSQ)

A self-report questionnaire, the Norbeck Social Support Questionnaire (NSSQ), using a Likert scale, was employed. Respondents rated each network member on three subscales of social support, namely affect, affirmation, and aid (Norbeck *et al*., 1981; 1983). The instrument was language/culture validated to Swedish circumstances (Berterö, 2000; Johansson & Berterö, 2002).

Data analysis; content analysis

The interviews were transcribed verbatim and the text was analyzed using qualitative content analysis (Mayring, 2000; Krippendorff, 2004), which was intended to describe and discover the variation in perceptions. The content of the domains in the NSSQ questionnaire (affect, affirmation, and aid) described by Kahn (1979) and Norbeck (1981) provided a framework for understanding the participants' own experiences and perceptions of social support and assisted the deductive-inductive analysis (Mayring, 2000; Krippendorff, 2004). Data not deductively covered by the chosen framework formed the basis for developing categories

inductively. The analyses were based on openness for variation in data, and a search for patterns, regularities, and contradictions by comparing statements from different participants (Mayring, 2000). To increase the trustworthiness of the findings, 'investigator triangulation', with analysis of the data by two researchers independently, was used (Patton, 2002) and showed strong agreement. If needed, findings were discussed until a consensus was reached.

Statistics

Demographic variables were summarized and presented with median and range. All results were reported as means ± standard deviation of the mean (SD). Differences in the subscales, composite variable scores on the NSSQ, and comparison of means of independent groups were tested with ANOVA and Student's t-test. For categorical data, a χ^2- test was used to assess whether there was a significant association between each of the measures assessing social support and functional network properties, and for discontinuous variables Fisher's exact test was used (Altman, 1991; Norbeck, 1995) when needed. $P < 0.05$ was considered statistically significant. Statistical Package for the Social Science (version 15;SPSS Chicago, IL, USA) version 15 was used for statistical analysis.

RESULTS

The study population comprised 34 foreign-born persons, 24 men and 10 women, aged 36-73 years (m 56.7 yrs, Table 1), and only one woman aged >65 years. Most originated from countries in the Middle East or former Yugoslavia (29/34). The median time of residence in Sweden was 14.5 years (range 3-50 years). Most were married (73.5%) and a third were retired (35%). All except one had children, and about half of the group had grandchildren. Duration of disease varied from 1-36 years (m= 7.4 years for the women vs.13.4 years for the men), and most were being treated with oral agents or diet.

Please insert Table 1 about here

Quantitative results

Self-reported social support and networks measured by NSSQ

Three persons did not respond to the NSSQ and one responded only partially, as they feared the document could be used for other purposes than the intended one because of previous negative migrational experiences.

Studying the figures measured by NSSQ (Table 2) no significant differences were found. When calculating the figures according to gender, women scored higher on emotional support, aid, and network than did men. There were no differences between married and unmarried men and women, and there were no significant correlations between marital status and emotional support. However, when studying the influence of marital status by using Pearson's correlation, a significant difference was found regarding aid (p= 0.018). Having children or grandchildren gave no significant difference regarding aid or emotional support.

Please insert Table 2 about here

The participants answering the NSSQ (n=31) listed a total of 178 people in their networks. The mean number of people in each network was 5.74. These were mainly family members. The size of the network ranged from 1 to 14 members. Relatives (spouse and family) and friends were listed most frequently, 59.6 % and 17.4 %, respectively (Table 3).

Twenty (74 %) of the married and common law wives/husbands listed their spouses as the first person in their network. The relationships with the network persons lasted from two years to five years and the majority had lasted for more than five years. Women had an average relationship duration of 4.83 and men an average duration of 4.77.

Please insert Table 3 about here

An additional finding was that 41.7 % of the participants had lost an important relationship in the previous year. The support estimated by the participants regarding these losses was from ‘quite a bit’ to ‘a great deal’ (m=2.03) on a 5-point scale.

Qualitative findings

Two categories were inductively developed to present social support. They were the meaning of support, and support influencing the entire life-situation when having DM. Those categories show that support sometimes converged with the NSSQ domains, but also that support expressed by the informants sometimes departed from the domains and was more broadly presented and interpreted.

The meaning of support

The meaning of support, for both men (M) or women (W), was mainly expressed in relation to medical support; e.g. regular control of the disease and treatments as well as informative support in terms of knowledge about how to manage the disease.

> The support I need most is firstly to learn to know how to organize my diabetes so that everything will be fine in my daily life. A plan to be able to manage diabetes, regular checks and investigations by specialists…learn to know what factors contribute to increased blood sugar…(M, Palestine)

There was an issue expressed about limited support. Men focused more on informative support such as communication about DM, not only support from GPs. They wished to focus not only on the disease, but on the whole system. Several of the women discussed the importance of social support in terms of financial aid/assistance, e.g. more expensive food, from the regional social insurance office that aided allowance but also such aid as sick-leave and survivor's pensions for spouses.

> When you have diabetes you need to think more about yourself, about the diet, about your life, …in particular, food for diabetics is expensive…3-4 times more expensive than ordinary food…Economic support is what you need (W, Bosnia)

In the interviews, participants claimed that the need for support was individual and varied between people due to the disease and the severity of the disease.

Women expressed, in contrast to men, that men needed more support as women perceived themselves as having better knowledge and as being more emotionally focused.

According to the women, men did think more about themselves, but the women thought about everybody around them first, and women were, for example, used to following a regular scheme.

> I think that men need more support and help. A woman is more knowledgeable when it comes to cooking…she is able to cook healthy food for herself …(W, Iraq).

Persons <65 years of age, despite gender, perceived that younger persons needed more support as they were going to live longer, were less experienced, and were thought to have less knowledge about the disease, than elderly persons. They also stated that the need would increase over time in relation to deteriorated health status; this statement was confirmed by the elderly men interviewed. Men aged <65 years discussed the importance of informative support while elderly men >65 years emphasized support with information about diet and in changing dietary habits, particularly with practical aid in cooking. They asked for courses or support where they could learn by doing

Women focused more on situations where informative support was described in the contact with a diabetes specialist nurse or other kinds of health care staff on the diabetes care ward.

Persons aged <65 years also discussed the influence of emotional support given by health care staff when informing about DM at regular follow-up visits, and talked about opportunities to ask questions.

> I am going to check-ups 2 times a year and if I have some questions then I ask them, but otherwise…if I have some questions then there is a telephone so I can call and ask what to do…(M, Finland)

Several women also commented that they had experienced lack of support in contact with the health care centres and they were disappointed with their insufficient competence in diabetes care.

Most of the participants did not identify non-supportive situations but instead said they were satisfied with the health care delivered in Sweden:

> I am satisfied with that I was here and was informed about having diabetes, and health care here in Sweden offers very much support for us that have diabetes (W, Bosnia).

However, those who did identify non-supportive situations were concerned with the relationship and communication with the physician. The participants described physicians as ‘distant/reserved’ ‘not attending’ to them, ‘just takes tests’ and ‘showing lack of empathy’.

> I haven’t got any help or support. The only thing is when I go to the hospital, then they measure blood sugar, otherwise I haven’t got anything.
>
> At the health care centre, they just take blood tests and measure blood sugar, and it is just that (M, Palestine)

Support influencing the entire life-situation when one has diabetes mellitus

In the interviews, support experienced after being diagnosed with DM was described by the participants, irrespective of duration and the year when diagnosed, as very limited or non-existent, and this negatively affected their life situation. Mainly elderly men aged >65 years, had been diagnosed abroad. They described their experience of searching for help and stated that the health care systems between the countries were completely different: Sweden is more service minded but in their home country there was limited support

Most of the participants had been diagnosed in Sweden, and had not suspected DM. Often the disease was a secondary finding to other health problems such as for example faintness, and infection. Many said that they had not felt so well and the reactions to the diagnosis were described as varying from 'surprised' to being 'scared', 'worried' or 'not knowing' what it was about.

In most cases, the diagnosis had been made by a physician at a health care centre in primary health care and the typical support described was that he 'informed about the diagnosis and prescribed medicine'. Thereafter the person was referred for further information. Informative support from staff specializing in diabetes care, either at day care units at the hospital or in diabetes clinics in primary health care, about managing the disease was received later for the majority of patients, in many cases not until 1-2 years after being diagnosed. In this contact, many of the participants experienced adequate support that was particularly informative but also emotional.

> …One year ago I came to the hospital (diabetes clinic) …two doctors explained what diabetes is and how to manage it…(M Palestine).

Both men and women desired support from health professionals in diabetes care (physicians and diabetes specialist nurses) and emphasized the importance of competence in DM. In some

cases this was combined with support from the closest network, such as the wife or husband and children. Elderly men aged >65 years also wanted support and understanding from the family, especially the wife.

Most of the participants stated that the support perceived and given had a positive influence on their entire life-situation. Those aged <65 years said that support made them live longer, better, and more healthily and that they had learned to live with the disease, while elderly men (aged >65 years) said that support made them feel better.

Only one person in the study described being given adequate support from the time of being diagnosed. This diagnosis was made by the physician at an occupational health service and the person was directly transferred to the diabetes care team at the health care centre where diabetes classes lasting one week followed. Then there were regular checks by a diabetes specialist nurse and a physician.

> When I went to the company doctor, he told it. And then it was arranged that I would come to the diabetes specialist nurse here (at the health care centre) …this course that was arranged (by the diabetes care team) was good. I got a lot of information there…about food and exercise…// Yes, I'm tested every week…I have got it (DM) and I have to live with it…I need to go for regular checkups. (W, Finland).

Another factor of importance in relation to the need for support in DM, which also affected the total life situation, was the ability to communicate and the need to use interpreters and information material in the native language. This was particularly expressed by Arabic-speaking persons.

DISCUSSION

Foreign-born persons had low scores on the NSSQ regarding total emotional support, total aid and total function compared with Swedish-born persons (Hjelm & Berterö, 2009) and the normative population (Norbeck et al. 1983). The network size for most participants was limited. This is less than previously reported in studies using NSSQ (Norbeck *et al*., 1983; Primomo *et al*., 1990; Berterö, 2000; Hjelm & Berterö, 2009). However, the results are not comparable as none of the former investigations concerned a migrant population. Previously broken and limited social networks have been found among migrants (Hull, 1979; Sundquist, 1995; Kirkcaldy *et a*l., 2006), particularly in non-European refugees, compared to native people (Sundquist, 1995; Kirkcaldy *et a*l., 2006) and this could be the explanation of our findings as many had lost an important relationship during the previous year (42%).

Support was perceived as limited in general, particularly while being diagnosed/treated outside a specialized diabetes care/hospital. An information gap not filled until 1-2 years after the diagnosis was in some cases described. This is striking as national guidelines for diabetes care exist which recommend that health care teams specializing in DM should particularly focus on patient education as the organization for managing Type 2 DM in primary health care (Socialstyrelsen. 1999). The participants expressed a need for support by staff who specialized in diabetes care, and as previously discussed by patients with DM, competence in diabetes care was found to be limited in staff working in Swedish primary health care (Hjelm *et a*l., 2002; Hjelm & Berterö, 2009). Non-supportive situations concerned communication and relationships with physicians. Perceived lack of information or clear explanations might arouse emotions of anger and hostility (Vileikyte, 1999).

The focus on emotional support was low in our study, in contrast to a previous study of Swedish persons with type 2 DM (Hjelm & Berterö, 2009). This might be related to different expectations of health care staff in persons from different cultures. The focus on learning to manage the disease could be related to differing needs as limited knowledge about DM and the body has been indicated in migrants with DM compared to Swedes (Hjelm *et a*l., 2003; Hjelm *et a*l., 2005). On the other hand, focusing on regular follow ups of DM might include emotional support by encounters with health professionals specializing in diabetes care who can give both aid and affirmation (Kahn & Antonucci, 1980). This is supported by the fact that non-supportive situations were seldom described when being cared for in specialized diabetes care, and by the satisfaction expressed with support given in Swedish health care compared to lack of support experienced in the home countries.
Age, duration of disease, and being gainfully employed had limited influences on the results, despite the heterogeneous sample studied. One exception was elderly men's desire for information about diet and practical aid in preparing food, which needs to be considered in planning of diabetes classes. Another dissimilarity was that persons aged <65 years complained about high costs related to DM, e.g. more expensive food, possibly related to dissimilarities in many participants' own living conditions (Hjelm *et a*l., 2005). In Sweden, costs for healthy food (e.g. vegetables and bread rich in fibre, fat-reduced food) recommended for persons with DM and people in general are higher than for other types of food. Many foreign-born persons in Sweden, particularly non-Europeans, live in strained economic situations due to unemployment, and dependency on social allowances (Socialstyrelsen, 2009), which needs to be considered in diabetes care. Co-operation with social workers might be needed to give adequate support.

The number of participants can be seen as limited for the purposes of statistical analysis (Altman, 1991/1999). However, the quantitative data collected was not intended for statistical

generalization; instead, a more complete understanding of the complex concept of support/social support can be reached by using the principle of complementarity (Patton, 2002; Teddlie &. Tashakkori, 2009).

Some participants did not respond to the NSSQ (three completely, one partially) as they were sensitive about recording their opinions and feared the document might be used for other purposes than the intended. This was related to previous experiences of political persecution.

The studied migrant population consisted mainly of persons from the former Yugoslavia and Iraq (83%) with a median time of residence in Sweden of 14.5 years and compared to the migrant population in Sweden reflects a refugee population of later date (SOS, 2008). Thus, the sample is biased, but considering that previous studies of prevalence of DM in migrants in Sweden have shown higher figures in refugees from non-European countries, particularly in the Middle East (Wändell & Gåfvels, 2007; Glans *et a*l., 2008) but not in European labour migrants (Hjelm, 1998), this is expected. When studying the demographic characteristics of our sample it is found that all women, except one, were <65 years of age, indicating another bias. However, the migrant population is younger, with a lower proportion of females compared to Swedes (SOS, 2008). The sample represents migrants in Sweden who are affected with Type 2 DM. The data have been carefully conducted and analyzed, so the results may be transferred to other groups similar in characteristics (Patton, 2002).

Recommendations following the study are as follows. First, it is important to develop an organization where foreign-born person with type 2 DM are given adequate support, both with regular follow-up of the disease and by providing information to patients about how to self manage the disease. This should be done by health care professionals specializing, and particularly trained in diabetes care, without delay, from the very first moment of being

diagnosed. It is also important to investigate the individual's own perspective on what support is desired and needed, and to consider the importance of aid, both practical and informative, in developing healthy life-style habits in the context of socio-economic factors. Health care professionals should also be aware that foreign-born persons define social support as social support within their context from their own point of view and using their own terminology.

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Conflict of interest statement

None.

Contributions

Study Design: CB & KH

Data Collection: KH partly

Analysis: CB & KH

Manuscript writing: CB & KH

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Table I. Characteristics of participants

Variable	Women = 10		Men n = 24	
Age (years) [1]	56.0	(36-73)	56.5	(42-73)
Duration of diabetes (yrs) [1]	7.0	(1-17)	12.0	(2-36)
Treatment n (%)				
Diet	1.0	(10.0)	5.0	(20.8)
Oral drugs	5.0	(50.0)	11.0	(45.9)
Insulin	3.0	(30.0)	6.0	(25.0)
Combination of oral drugs and insulin	1.0	(10.0)	2.0	(8.3)
Gainfully employed n (%)	2.0	(20.0)	9.0	(37.6)
Unemployed n (%)	2.0	(20.0)	5.0	(20.8)
Sick leave n (%)	1.0	(10.0)	2.0	(8.3)
Old- age pensioners n (%)	3.0	(30.0)	8.0	(33.3)
Students n (%)	2.0	(20.0)	0.0	
Family circumstances n (%)				
Unmarried/living alone	0.0		0.0	
Married/cohabitant	8.0	(80.0)	19.0	(79.2)
Divorced	1.0	(10.0)	4.0	(16.7)
Widow/Widower	1.0	(10.0)	1.0	(4.1)
Children n (%)	10	(100.0)	23	(96.0)
Grand children n (%)	7	(70.0)	12	(50.0)
Percent experience loss		60.0 %		25.0 %

[1] Median (range)

Table II. Means and standard deviations of scores on the NSSQ (N =31)

Variables	WOMEN n=10		MEN n=21		TOTAL N=14	
	Mean	SD	Mean	SD	Mean	SD
NSSQ Variables						
Network size	6.80	2.20	5.23	3.44	5.74	3.15
Emotional support	106.30	42.43	83.76	52.80	91.03	50.13
Aid	46.27	26.95	41.55	27.47	43.22	29.93
Total function	154.80	68.65	125.52	77.74	134.96	75.07
Total network	67.20	23.17	49.66	32.99	55.32	30.92

Table III. Social support (numbers of persons in personal network listed by the informants (N=31)

Source of support	No.	Percentage of total network
Spouse/partner	22	≈ 12.4
Family	84	≈ 47.2
Friends	31	≈ 17.4
Workmates [a]	9	≈ 5.1
Neighbours [a]	2	≈ 1.1
Health-care providers [b]	26	≈ 14.6
Counsellor [b]	3	≈ 1.7
Minister/priest [b]	1	≈ 0.5
Total	178	≈ 100

[a] Could also be called non-professionals.
[b] Could also be called professionals.