



CARERS OF PERSONS WITH HEART FAILURE A FOUR NATION STUDY

IACO International Alliance
of Carer Organizations

2017



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Executive Summary

Heart failure is a common condition worldwide, with a prevalence of 1-2% in many countries, increasing to 10% and above among persons over the age of 70. Heart failure is caused by an underlying disease, most often a cardiovascular condition, which leads to a failure of the heart muscle to either pump sufficiently or to relax and fill efficiently or a combination of both. As a result, the heart is unable to provide sufficient circulating blood to all tissues in the body. Heart failure, particularly in the more severe stages, is associated with a significant impact on the functional capacity of the person with the condition. This corresponds to increasing need for support with daily activities and self-care behaviors such as monitoring symptoms of deterioration, following prescribed medication, and exercise routines. Support for carers, a term used around the world interchangeably with caregiver or family caregiver, leads to better outcomes for persons with heart failure regarding the increased health-related quality of life and improved survival.

However, there are two sides of the coin and carers may themselves experience distress related to the caregiving situation. The value of family caregiving to persons with heart failure and society must be evaluated in light of the costs to carers' health, and psychosocial well-being. Carers in general, and heart failure carers, in particular, are an unrecognized group. The impact of heart failure on carers is an under-studied area when compared to carers supporting family members with conditions like cancer, stroke, mental illness, and dementia. Despite recommendations from national and international heart failure guidelines that the health care should support and involve carers more directly in patient care, this is rarely done. Many carers to persons with heart failure report feeling neglected and need more education and support from society, employers, and health care professionals.

Over the last several years, clinical researchers and experts in psychometrics have developed a tool to assess the influence of caregiving in heart failure with support from Novartis. The Caregiver Questionnaire for Heart Failure tool has been developed with qualitative input from heart failure carers and has been psychometrically tested in several steps. The purpose of this international study was to describe the effects of caregiving for a person with heart failure

on the daily life and well-being of family carers and to explore the factors that influence carers' outcomes.

The Caregiver Questionnaire for Heart Failure, along with other questionnaires, was pretested in four different countries with carer and patient organizations for modifications to elicit better information regarding the effects of heart failure on the carers' situation.

This research study was initiated and implemented by the International Alliance of Carer Organizations (IACO), a coalition of 14 member nations committed to building a global understanding and respect for the vital role of family carers.

The study was conducted in Australia, Canada, United Kingdom (UK) and United States (US) and IACO collaborated with carer and patient organizations in the four countries. The leading organizations were: Carers Australia, Carers Canada, Carers UK, National Alliance for Caregiving (US), WomenHeart: The National Coalition for Women with Heart Disease (US), Pumping Marvellous (UK), Canadian Home Care Association, The Heart and Stroke Foundation of Canada, and Heart Support-Australia Ltd.

The design was a quantitative cross-sectional study using a web-based survey inviting family carers in four countries to participate. Carers, defined as an individual who provides unpaid care to support a relative or friend, 18 years or older diagnosed with heart failure, were eligible to participate in the survey. The complete survey can be found in Appendix A.

The survey included four sections addressing demographic aspects of carers and persons with heart failure they cared for, the extent and impact caregiving had on their daily lives, caregiving tasks, work situation, the degree the carer felt he/she had control over the heart condition, and their preparedness for caregiving and well-being. Data collection using a web-based survey format was conducted between February and March 2017.

Results

The survey included complete data from 519 carers. The mean age of carers was 58 years, and 79% of them were women. With regards to the relationship with the person with heart failure, almost half of the carers were partners, one in five were adult sons or daughters and one out of ten were parents or grandparents.

Many carers were working, either full-time (30%) or part-time (15%). Almost one-third of the carers were retired (30%). Fourteen percent were involved with full-time caring for the person with heart failure. Two-thirds of the carers (66%) stated that they had never had to leave a job due to caregiving. But for one-third, working life was clearly affected by caring tasks.

The majority (61%) of carers had a college or university education, and one-third (30%) had a high school degree or qualifications.

The mean age of the persons with heart failure was 69 years. The persons with heart failure whose carers participated in this study were quite ill, with eight out of ten having co-morbidities such as diabetes, depression, or musculoskeletal problems.



Most carers either lived with the person with heart failure or nearby. Three carers out of four were the primary carer for a person with heart failure, and two-thirds had been caring for that person for more than two years. The mean care was 22 hours per week. Thirty percent of the persons with heart failure needed constant care, and 15% needed less than one hour per week. Carers helped with a substantial number of activities of daily living (ADL) such as bathing and dressing. In addition, carers helped with instrumental activities of daily

living (IADL) such as cooking, shopping, and managing finances as well as medical and/or nursing tasks. Half of the carers found it difficult to help with these tasks.

While one out of five stated that they had chosen to become a carer, the survey revealed that the majority of the carers just had to take on the role (81%). There was no significant correlation between feeling prepared to be a carer and having a choice to be a carer.

Half of the carers perceived no control over the heart failure condition, 27% experienced some control, and the rest perceived they had good control. Less than one-third of the carers felt they were supported by someone to balance their well-being. Half of the carers reported that caregiving had made their health worse, while the remaining carers did not think caregiving had affected their health.

Policy Recommendations

This survey by the International Alliance of Carer Organizations (IACO), in collaboration with 4 of its 14 member organizations and their partners from heart failure organizations, is the first international study describing the impact on carers of assisting a person with heart failure. Carers play a vital role in self-care of heart failure patients. Self-care, such as adherence to medical treatment, exercise training, routine self-monitoring and symptom management prolong survival significantly in persons with heart failure. Greater involvement by others like family and friends, besides the person with heart failure, has been found to improve self-care significantly. The importance of carers and social support in heart failure self-care, as well as carers' under-representation in current self-care programs, has been identified in the research literature. This survey found that many carers felt unprepared for many of their caregiving tasks and were not in control of the heart failure condition.

Based on the findings of this survey, we make the following recommendations:

What can health care professionals do?

- Engage carers as an essential member of the heart failure team and acknowledge their critical role in the implementation of the treatment plan for persons with heart failure.
- Integrate a routine caregiver assessment into existing assessment processes and facilitate specific and targeted support to prevent physical and psychosocial health decline in carers.
- Support carers in navigating the system and helping them to gain access to existing services and supports. This includes carers' need for education about the heart failure condition, its treatment and the importance of self-care and psychosocial support.

What can governments and healthcare system decision-makers do?

- Examine the structure and viability of a navigation/information system to ensure caregivers know about and can easily access services and information when and as they are needed.
- Develop and test user-friendly technology in the home setting to support patients' and caregivers' needs, especially in the case of distance caregiving.
- Enhance data collection and research to inform the development of evidence-based policies and programs for carers, particularly among vulnerable and underserved populations.
- Develop policy measures that will not only reduce the financial burden of caregiving but also help protect future income for those who need to leave their jobs on a temporary or permanent basis because of caregiving responsibilities.
- Ensure fairness and affordability by integrating health and economic impact of caregiving into the cost-benefit analysis of health interventions and programs of support.
- Implement incentives for employers to include support for working caregivers in their human resource strategies.

What can private, voluntary organizations and community associations do?

- Improve awareness and understanding of the role and impact of caregiving by recognizing caregivers in their awareness and advocacy campaigns.
- Promote evidence-based tools and resources to facilitate physicians, clinicians and care providers in recognizing and supporting the patient-caregiver dyad.
- Invest in education, training, and skills development initiatives to better prepare carers for their caring role.
- Develop a program of work targeted at employers to encourage greater understanding of the challenges facing carers juggling work and care and various supports they can provide.
- Provide flexible health and support services to enable carers to be able to juggle aspects of their lives.

What can carers do?

- Be actively involved in decision-making and have a care conversation with the person you are supporting and members of their health care team to understand your role in their clinical care and future well-being.
- Be your own advocate and learn how to support your health and well-being. Learn signs of caregiver stress and find out what supports are available for you.
- Understand short, medium and long-term care options, and support persons with heart failure in following the directions of their healthcare providers regarding medication and lifestyle changes.



Introduction

Heart failure is a clinical syndrome which may cause symptoms such as dyspnea, oedema, and fatigue. Heart failure is caused by an underlying disease, mostly cardiovascular, either leading to failure of the heart muscle to pump sufficiently, failure to relax and fill efficiently or a combination of both. Heart failure, particularly in the more severe stages, is associated with a significant impact on the functional capacity of the patient. This corresponds with increasing needs for support with a number of daily activities and self-care behaviors such as monitoring symptoms of deterioration, following prescribed medication and exercise advice [1-3]. Heart failure is a common condition worldwide, with a prevalence of 1-2% in the population in many countries; rising to $\geq 10\%$ among persons above 70 years of age. Many of the individuals with heart failure worldwide daily receive care and support from family members and/or friends. In home-based management, up to 70% of persons with heart failure are dependent on a family carer, usually the spouses/partners or other close family members [4-6].

The family carers provide a wide-range of tasks for those individuals with heart failure to help facilitate their health behaviors, social and emotional health, relationships, and quality of life. The positive influence of family caregiving on heart failure outcomes has been shown as improved health-related quality of life [7], reduced rates of hospitalization and improved survival [8, 9]. A recent study found that higher levels of family functioning and better relations were independent predictors of better emotional quality of life, and greater knowledge about heart failure among family members' was associated with less depressive symptoms in the person with heart failure they cared for [7]. Conversely, inadequate family support has been associated with unfavorable outcomes in the individuals with heart failure and that approximately 20% of hospital readmissions may be attributed to inadequate social support [10, 11].

While there are benefits for persons with heart failure, there are costs for carers. A number of surveys over the last decades have documented the significant burden heart failure imposes on carers. The carers have been found to have numerous

unmet needs and to experience stress due to the unpredictable medical situation of the person with heart failure. Carers also often feel ignored and neglected by health care professionals. This daily reality can lead to physical and psychosocial distress and reduced well-being for the carers. Almost half of spousal and family carers of persons with heart failure have been reported to experience some depressive symptoms [12-14]. Common causes of reduced mental well-being are a perceived low degree of control over the health outcomes of the patient and the lack of time available for activities with friends [15, 16]. Carers also frequently express a need for greater knowledge of heart failure to better support the patient, to cope with stress and distress, and to feel more prepared for dealing with all kinds of caregiving tasks [17, 18].

A recent review estimating costs for family caregiving in persons with heart failure estimated that the total cost of family caregiving ranged from \$12,270 to \$20,319 (US) for a person with heart failure annually [19].

Having support from a carer is crucial for individuals with heart failure. Heart failure self-care, such as adherence to medical treatment, exercise training, routine self-monitoring and symptom management, prolong survival significantly. Greater involvement by the family has been found to improve self-care significantly. At the same time, it should be acknowledged that caregiving could affect the carer negatively and cause emotional distress [20-22].

Measuring the role of carers in supporting individuals with heart failure and the impact of providing that support on the well-being of carers is becoming increasingly important. Although instruments exist which measure multiple aspects of caregiver burden, there is little evidence of their content validity among heart failure carers, with most lacking qualitative input from heart failure carers during the development. A conceptual model was developed by clinical researchers with financial support from Novartis Pharmaceuticals through interviews with heart failure carers regarding the relevant areas where caregiving was affecting the carers' lives.

Based on this model the Caregiver Burden Questionnaire for Heart Failure version 4.0 (CBQ-HF v4.0) – a 26-item patient-reported outcome measure to evaluate the burden of caregiving for heart failure patients was developed [23]. A psychometric evaluation study to develop scoring and explore psychometric properties of this

tool was conducted, which resulted in a revision and renaming of the tool. The tool is now called the Heart Failure Caregiving Questionnaire (HF-CQ) and consists of 21 questions addressing how the carer situation has affected life in three domains: physical, emotional/psychological and lifestyle [24].

The extraordinary value of family caregiving to the health care system and to persons with heart failure, as well as the costs it may impose on the carers' own health and well-being, deserves more attention from health care professionals. Yet, the impact of heart failure on carers remains a relatively under-investigated area, and international comparisons are lacking.





Methods

Study Purpose

The purpose of this international survey study was to describe the effects of caregiving for a person with heart failure on the daily life and well-being of a family carer and to explore the factors that influence a carers' outcomes.

Design

This study had an observational design. Carers from four countries: Australia, Canada, the United Kingdom and the United States were invited to participate in a web-survey. The study was initiated and administered by the International Alliance of Carer Organizations (IACO), a coalition of 14 nations committed to building a global understanding and respect for the vital role of family carers. IACO collaborated with carer and patient organizations in the four countries. The leading organizations were: Carers Australia and Heart Support-Australia Ltd. from Australia; Carers Canada, Canadian Home Care Association, and The Heart and Stroke Foundation of Canada; Carers United Kingdom and Pumping Marvellous from the United Kingdom; and the National Alliance for Caregiving and WomenHeart, The National Coalition for Women with Heart Disease from the United States.

Procedure for Data Collection

The survey included four sections addressing demographical aspects of carers and patients, the extent and impact of caregiving on daily life, caregiving tasks, work situation, experienced control over the heart condition, and preparedness for

caregiving and well-being (see Appendix A).

Data collection using the web survey was open between February and March 2017. A convenience sample was applied, and the carer organizations and heart failure patient organizations in each country collaborated on promoting and advertising the survey.

Australia



Carers Australia partnered with Heart Support-Australia Ltd. in the engagement with carers for the study. A joint media release, with a link to the survey, was disseminated to Australian media (broadcast, print and online) on February 2, 2017. The media release was published on the Carers Australia website and as a Latest News Item. A co-branded targeted letter was sent to the 650 members of Heart Support-Australia in the lead-up to February 2, 2017, via email or in the post.

The media release and a targeted email, with a link to the survey, was sent by Carers Australia to the eight state and territory Carers Associations for distribution through their networks, and Carers Australia's substantial key stakeholder list. The survey was also promoted in the March edition of Carers National News (e-newsletter with over 4,200 subscribers).

Heart Support-Australia sent out a link to its newsletter subscribers and email database, with the link reaching over 650 members and stakeholders directly. It also provided a service where respondents without access to the internet could call the office and have their responses counted.

Both organizations posted daily to Twitter and Facebook, and Heart Support-Australia promoted via LinkedIn. Stakeholders across Australia posted separately to social media or retweeted and shared posts. Carers Australia Facebook posts showed 2,347 views and tweets to 1,350 followers.

Canada



Recruitment of caregivers in Canada was a collaborative effort between several national and provincial heart organizations, patient and caregiver groups across the country. Led by Carers Canada, the Canadian Home Care Association and the Heart and Stroke Foundation of Canada, carers outreach were further supported by BC Heart Failure Network, Caregivers Alberta, Caregiver Exchange, Canadian Heart Failure Society, CBI Health Group, Centre de Sante et de services sociaux Cavendish, Change Foundation, Health Charities Coalition of Canada, Family Caregivers BC, HeartLife Foundation of Canada, Ontario Caregiver Coalition, Saint Elizabeth, The Caregiver Network and Research on Aging, Policies and Practice research program at the University of Alberta.

The survey was promoted through multiple channels. Targeted e-mails were sent to collaborators' members and affiliates with an invitation to participate and/or share the survey. A general call to action through the collaborator's website, newsletter, and Twitter were also used to drive visitors to the survey. Further, Facebook ads through the Heart and Stroke Foundation of Canada's account were utilized to engage key audiences across Canada.

United Kingdom



Carers UK and the Pumping Marvellous Foundation were leading the work in the UK on the project. Both organisations are carer and user-led respectively. Both organisations used their networks and social media platforms to broadcast engagement in the project. Carers UK posted a news story on their website and tweeted regularly to their 45,000 Twitter followers. Carers UK supports carers of all ages and all conditions, meaning that a proportion of their contacts have experience of heart failure. Carers UK posted an item on its Carers Forum, which has 5,000 members and an item on its Facebook page with 31,000 followers. It also sent a tailored email to all those respondents in their research work who cared for someone with a heart condition around 135 and a segment of members indicating long term conditions – around 500 in total – and a link in the members magazine to 16,000 members. The Pumping Marvellous Foundation also has a rich and diverse series of networks. The Pumping Marvellous Foundation posted

a news story on their website and consistently used Twitter to create engaging conversations about the research work. PMF developed a creative image to share on their Facebook page with 15,000 followers many of whom have heart failure or are family members who care for someone with heart failure. They also created conversations in closed Facebook groups and contacted around 90 NHS Heart Failure teams. The overall approach from both organisations resulted in the numbers represented in the study.

United States of America



WomenHeart: The National Coalition for Women with Heart Disease posted the survey on its website and on Inspire, an online blog. The survey invitation was sent to the WomenHeart database of approximately 35,000 voluntarily registered members, the databases of five partner organizations, and WomenHeart social media channels. The National Alliance for Caregiving announced the survey and link in various email blasts to its email list and utilized social media channels to promote it. Furthermore, following the example of Carers Canada, the Alliance placed an advertisement on Facebook announcing the survey and directing the carers to the website.

Web Survey

The web survey used the cloud-based software SurveyMonkey and consisted of 73 items in four sections.

- Section A consisted of 13 questions addressing demographical data of the carer. Section B consisted of 6 questions asking about the person with heart failure who received care.
- Section C consisted of 24 questions targeting the caring situation with questions on caregiving tasks, such as Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) tasks, if carers perceived control over the heart failure, and were prepared to assume caregiving responsibilities.
- Section D consisted of 30 questions on how caring affected the well-being in different areas for the carer, the relationship with the patient and their work situation.

The survey was put together by the project group of representatives from carer and heart failure patient organizations in each of the four countries and a researcher with expertise in family nursing. Some questions were developed for this survey by the project group, and some questions were taken from a previous carer survey, Caregiving in the US (2015). Others were from validated instrument: the Cantril ladder of life question assessing quality of life on a scale from 1-10 [16]; the complete 8 item preparedness scale for caregiving scale [17] and the 21 item Heart Failure Caregiver Questionnaire(HF-CQ) [18]. The web-survey can be found in Appendix A.

Cantril's ladder of life

Cantril's ladder of life is to imagine a ladder with steps numbered from zero at the bottom to ten at the top. The top of the ladder represents the best possible quality of life, and the bottom of the ladder represents the worst possible quality of life [25].

Preparedness for caregiving scale

The preparedness for caregiving scale consists of 8 items asking carers how prepared they are for multiple domains of caregiving such as providing physical care, emotional support, setting up in-home support services and dealing with carer stress. Responses are rated on a 5-point severity response scale ranging from 0 (not at all prepared) to 4 (very well prepared). The scale is scored by calculating the total score of all items. Scores range from 0 to 32 with the higher scores indicating the more prepared the carer is for caregiving [26].

Heart Failure Caregiver Questionnaire

The HF-CQ consists of 21 questions addressing how the carer situation has affected life in three domains: physical (5 items), emotional/psychological (11 items) and lifestyle (4 items + 1 stem item). Items are scored on a 5 point severity response scale for how much life was affected ranging from 0 (not at all) to 4 (extremely). For item 15 the scoring is reversed as the item is positively worded: How much support have you had from family and friends. Each domain score was calculated as the sum of scores for items answered divided by the total possible score for items and multiplied by 100. The total score was the average of the sum of the three domain scores. The minimum score for both the domains and the total score was 0 and the maximum score 100. Higher scores indicate more negative effects of caregiving on carers life [24].

Data Analysis

Data from SurveyMonkey was exported to SPSS statistics 23.0. When carers were invited to participate in the study, the instructions stated that the survey would take 10-15 minutes to complete. The majority of the participants were able to complete the survey within this timeframe. Initially, data were reviewed for quality purposes, and missing data were explored. No missing data were imputed.

Data were expressed as frequencies for categorical variables, and mean and standard deviation (\pm) for continuous ones. Student t-test, Mann-Whitney, chi-square test and ANOVA with Scheffe post hoc analysis were used appropriately for the statistical analysis to explore factors influencing preparedness for caring, health-related quality of life and impact of the physical, emotional/psychological and lifestyle of carers. Pearson product-moment correlation coefficient and linear regressions were used. Variables with a correlation above 0.3 were used in the regressions as explanatory variables while preparedness, caregiver distress and quality of life were used as outcome variables. Data cleaning and all statistical analyses were performed by using IBM SPSS Statistics 23.0 (IBM Corp., Armonk, NY, USA). A p value < 0.05 was considered as statistically significant.

Limitations of the Survey

The survey was publicly advertised in all four participating countries. When analyzing the data, we found that the sample was highly selective with an overrepresentation of white female participants with high education and the majority of the carers being the partner of the patient. This is similar to what is seen in many previous research studies. The social selectivity of the sample limits generalizability to the majority of ethnic groups, male carers, and those with lower educational levels.

Findings

A total of 834 participants started to take the survey: 159 from Australia, 295 from Canada, 226 from the UK, 146 from the US and eight that did not state their country of origin.

As shown in Figure 1, in 120 of the surveys the majority of the data were missing, the participant started taking the survey and then stopped. In total, 714 valid surveys could be analyzed for demographic data on the carer and the patient (section A and B). However, there were also a lot of missing data in section C and D, on caring activities and impact on carers, leaving valid data for all questions in the survey in 519 carers.

When comparing the participants that responded to the full survey and those that only provided data on ADL and IADL support and/or demographic data, there were no differences with regard to the carers' age, gender, relationship to the person they cared for and educational level between those that provided a full data set and those with missing data. Those with missing data were significantly more often working outside the home compared to being retired, studying, or being a homemaker. They were also significantly more often than not the primary carer. There were also significant differences between the countries with regard to participants with missing data with 27% from Australia, 41% from Canada, 16% from the United Kingdom and 20% from the United States.

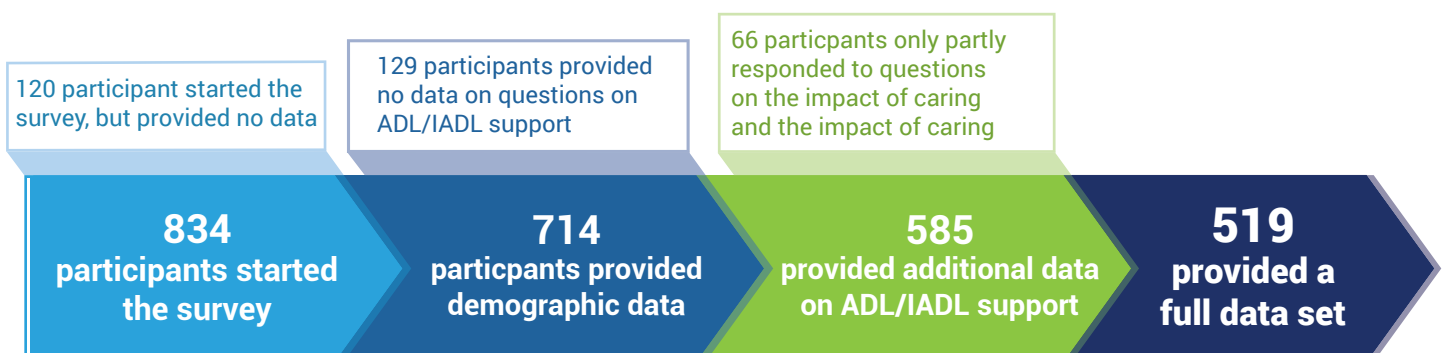


Figure 1. Missing data in the web-survey

Participating Carers

Demographical data on carers participating in the survey are presented in Figures 2 – 9 below. Carers mean age was 58 years, and 79% of them were women. With regard to their relationship with the person with heart failure, almost half (46%) of the carers were partners, 21% were children, and 9% were parents or grandparents. The employment status were 30 % were retired, 30% working full time, 15% part time and 14% full time caring for home and family. The majority (61%) of the carers had a college or university education, and one-third (30%) had a high school degree/qualification.

There were no statistically significant differences in the mean age of the carers or the patients they cared for in different countries participating in the survey. Also, there were no differences in the gender distribution of carers or the persons with heart failure.

However, there were some other significant differences with regard to employment status with carers in the US significantly more often working full time and less often being retired than in the UK and Australia.

There were also differences in educational level with 80% of the US carers were educated at a college or university level compared to between 50-60% in the other three countries. Comparisons between countries are in Appendix C.

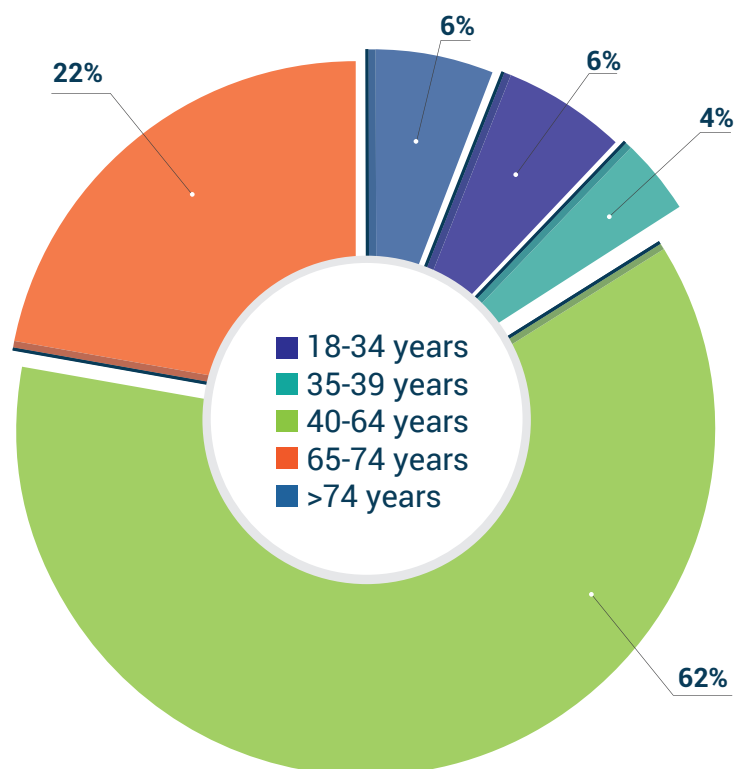


Figure 2. Age of the carers (n=714)



Figure 3. Gender of carers (n=714)

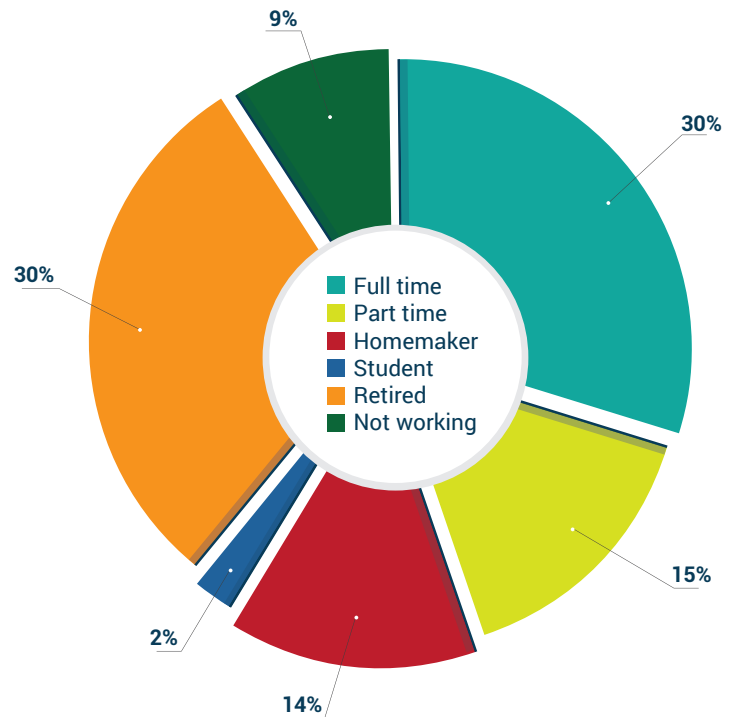


Figure 4. Employment status of carers (n=714)

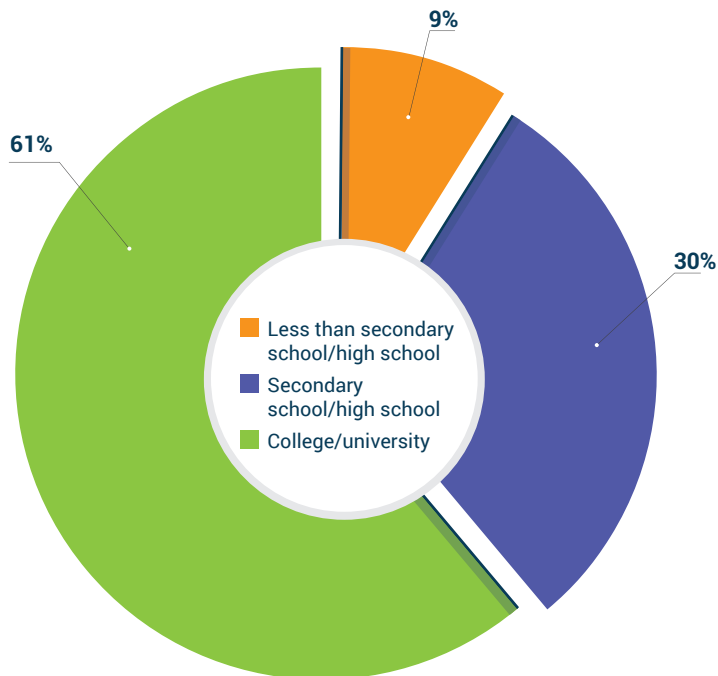


Figure 5. Educational level of carers (n=714)

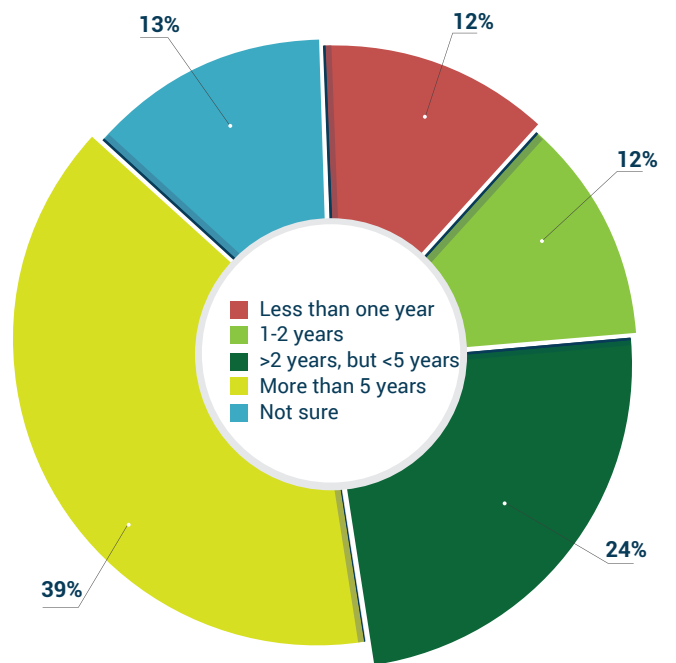


Figure 6. Years of caring (n=714)

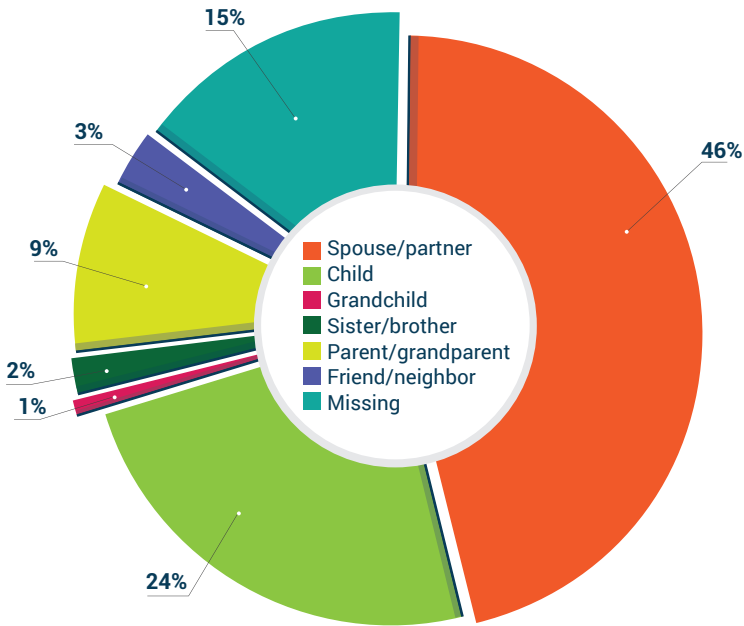


Figure 7. Relationship to person with heart failure (n=714)

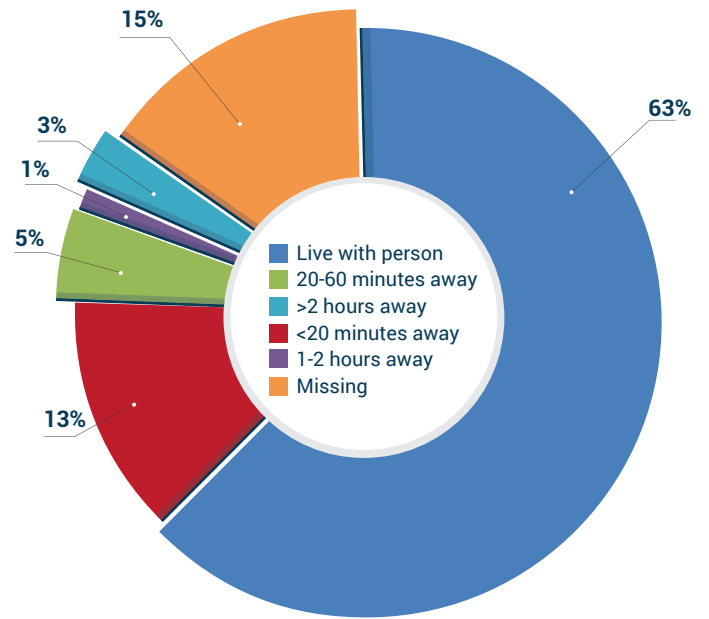


Figure 8. Living arrangements (n=714)

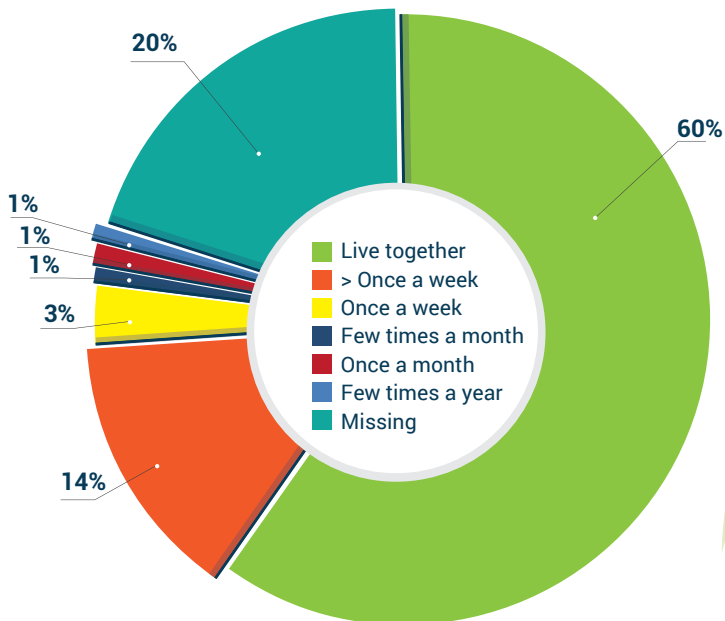


Figure 9. Frequency of visits (n=714)



Persons with Heart Failure

The mean age of the persons with heart failure was 69 years. Table 1 below shows that carers were assisting a severely ill group of persons with heart failure, with only 12% not having any other co-morbidities. The most common comorbidities were diabetes, depression and musculoskeletal problems/ arthritis. Almost half (44%) of the individuals had been hospitalized during the last 12 months. One out of ten was newly diagnosed with heart failure, and 37% had been diagnosed for more than five years. The comparisons between countries are in Appendix C.

Comorbidities	Percentage
Diabetes	181 (25%)
Musculoskeletal problems, arthritis	158 (22%)
Depression	141 (20%)
Lung disease	91 (13%)
Kidney disease	86 (12%)
Obesity	84 (12%)
No co-morbidities	82 (12%)
Stroke	78 (11%)
Alzheimer, other types of dementia	66 (9%)
Cancer	40 (5%)
Anemia	36 (12%)
High blood pressure	16 (2%)
Other	138 (20%)

Table 1. Comorbidities in the person with heart failure (n=714)

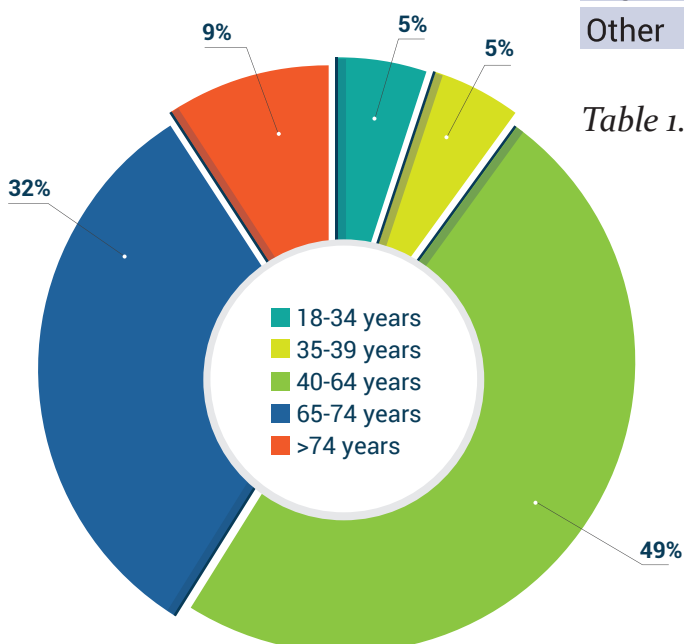


Figure 10. Age of the patient (n=714)

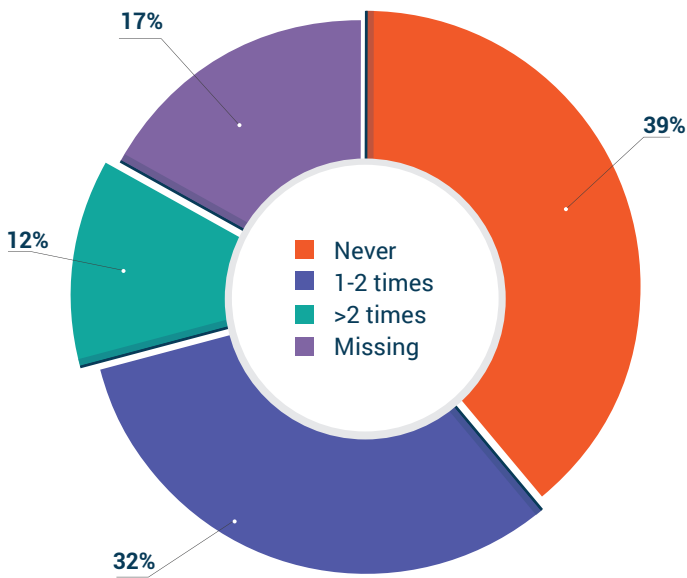


Figure 11. Hospitalized for heart failure during last year (n=714)

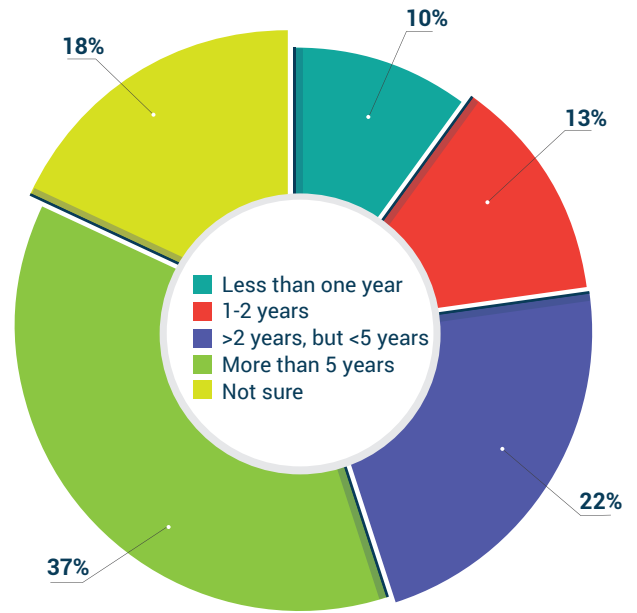


Figure 12. Time since diagnosis (n=714)

The Caring Situation

Most carers that responded to the survey were in close contact with the person with heart failure. Almost two thirds (63%) of the carers lived together with them. Of those that did not live in the same household, 21 % visited once a week or more often. Two-thirds (67%) had been a carer for more than two years, and three out of four were the primary carer for the person with heart failure. Thirty percent needed constant care, 15% needed less than one hour per week. For the rest of the individuals with heart failure, the mean time they needed care was 23 hours per week.

There were differences between the countries in the caring situation with 70% of carers in Australia and Canada, 75% in the United States and 85% in the United Kingdom being the primary carer. In Canada, significantly more carers had been a carer for less than two years. In the US, significantly fewer carers lived with the person with heart failure (66%) compared to Australia (79%), the United Kingdom (76%), and Canada (75%).

Carers helped with a substantial number of ADL and IADL tasks as shown in Figures 2 and 3 below. Most frequently with IADLs, shopping and housework being the most common tasks. Although half of the carers (50%) did not think it was difficult to help with these tasks, one-third (32%) thought it was somewhat difficult, and 6% thought it was very difficult.

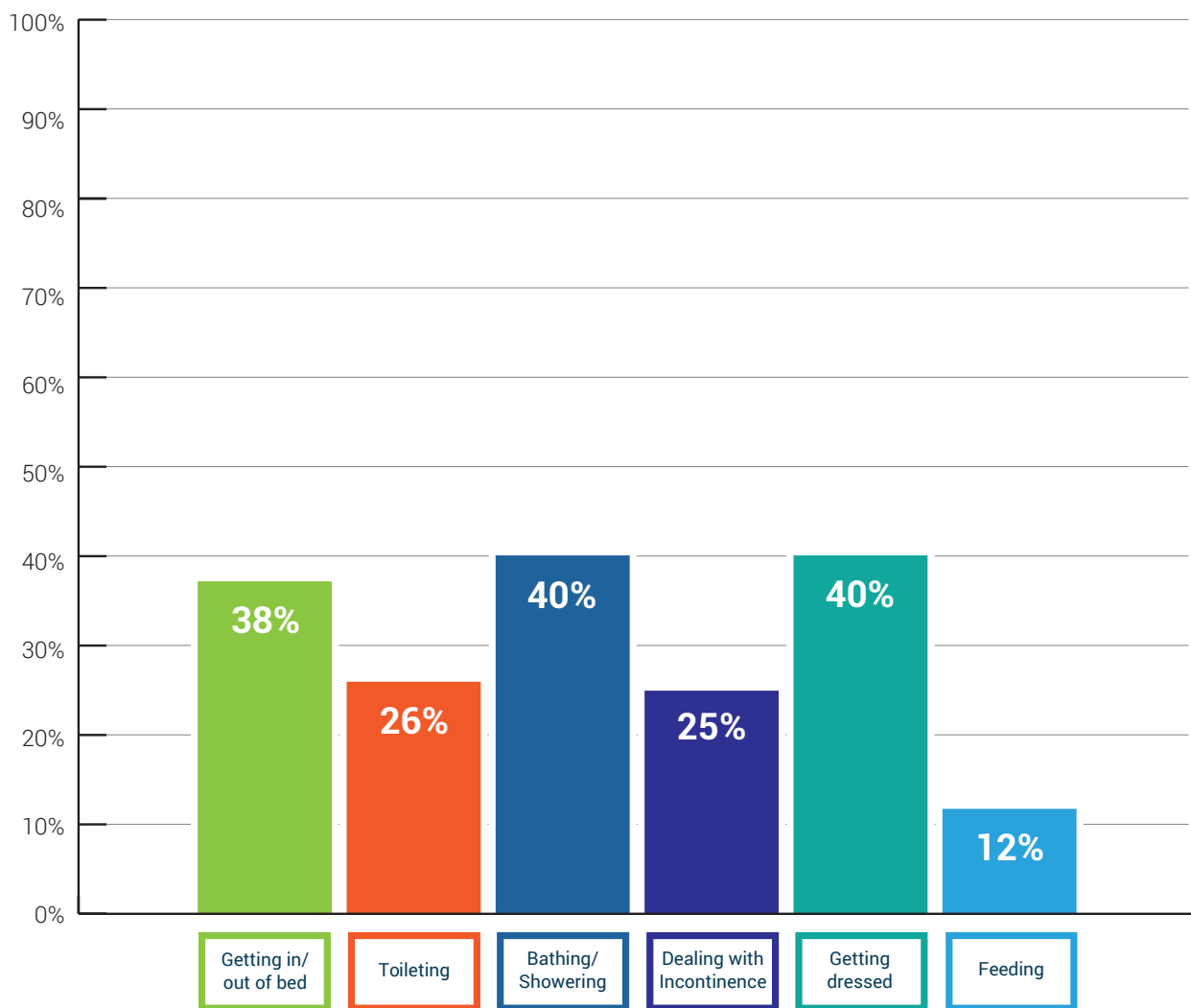


Figure 2. Percentage of carers that helped with Activities of Daily Living (ADLs) (n=550)

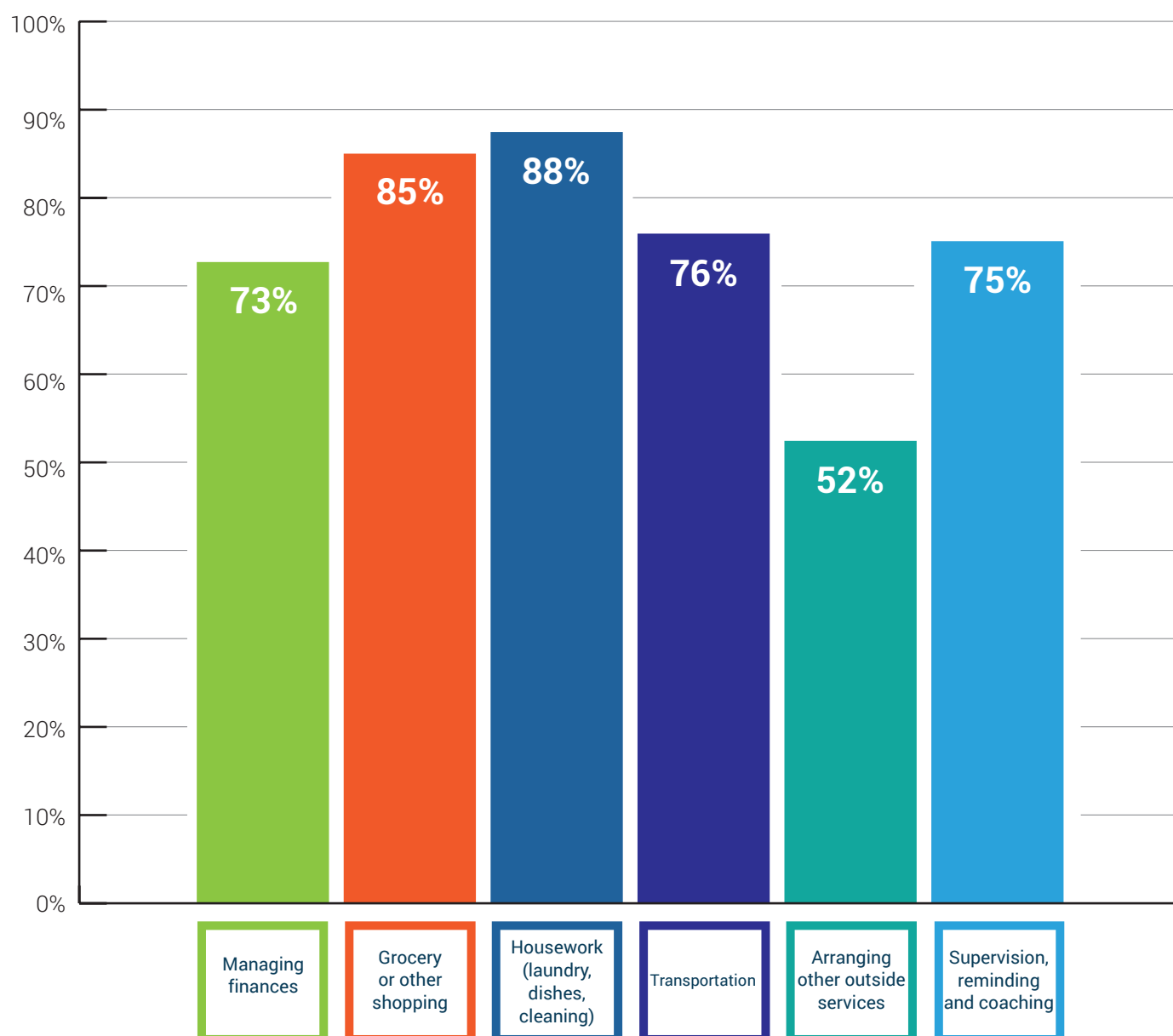


Figure 3. Percentage of carers that helped with different Instrumental Activities of Daily Living (IADL) tasks (n=550)

Many of the carers (70%) helped the person with heart failure with medical and/or nursing tasks such as preparing or giving medications like pills, eye drops, or injections, preparing food for special diets, wound care or monitoring symptoms and signs. Thirteen per cent experienced it to be very or pretty difficult, but most carers (65%) did not report that medical and/or nursing tasks were difficult. However, only one in five (19%) responded that they had been prepared for these tasks by health care professionals and one-third (37%) felt well prepared for the tasks.

Carers' Well-Being

One out of five (19%) stated that they had chosen to become a carer, but the majority just had to take on the role (81%). There was no significant correlation between feeling prepared to be a carer and having a choice to be a carer. There was also no correlation between how much caregiving affected your life and having a choice to become a carer. Choice in caregiving did not differ across the four countries, by age or gender. However, the relationship to the person with heart failure was significantly associated with choice. Very few of the partners/spouses (8%) stated that they had a choice to be a caregiver and only 1 in 4 of the children felt they had a choice.

Half of the carers (53%) perceived no control over the heart failure condition, 27% experienced some control, and the rest (20%) perceived they had good control. Carers in Canada experienced a significantly higher control than carers in the United Kingdom and Australia with 32% having good control in Canada and 14% in Australia and 16% in the United Kingdom.

Few carers (29%) felt they were supported by someone to balance their own well-being. There were significant differences between the countries. The United Kingdom had the lowest number of carers that felt supported at 21%, compared to Canada (27%), Australia (35%), and the United States (37%).

Carers scored their quality-of-life as 6.0 on the ladder of life from 0-10. There was a significant difference between the countries, with carers in the United Kingdom rating their quality of life as significantly poorer than the other three countries.

Figure 13 shows the carers self-rated health.

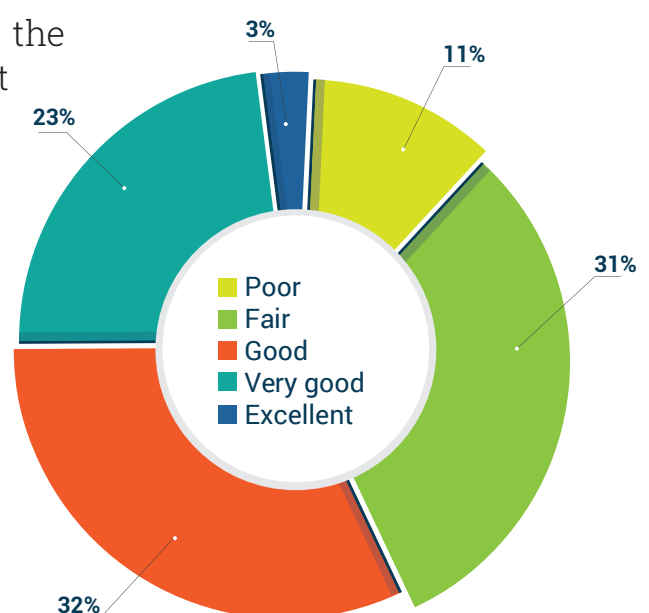


Figure 13. Carers' self-rated health

Less than half of the carers (45%) did not think caregiving had affected their health, but the rest thought it had made it worse (52%). Very few (3%) reported that caregiving had improved their health.

Significantly more carers in the UK (70%) also experienced that caregiving had made their health poorer compared to 40-50% in the other countries.

Carers scored the quality of the relationship with the person with heart failure they care for as 7.7 on a scale from 0-10. There was no significant difference between the four countries on how carers rated the relationship. A total of 39% experienced no benefits of caregiving while 44% experienced a little or some. In the United States, as many as 16% experienced a great deal of benefit from caregiving while in the other countries only 5% of the carers experienced great benefit.



Preparedness of Caring

The preparedness of caring in the whole sample showed a mean of 15.3 ± 7.6 . There was a significant difference between the countries, with carers in the United Kingdom feeling significantly less prepared for caregiving than carers in the US, **Table 2.**

Better preparedness for caregiving was significantly associated with higher educational level, living together or close, higher level of perceived control over the heart disease, better support in balancing well-being, higher quality of life and more potential benefits of caregiving.

Heart Failure Caregiver Questionnaire

The total scale of the Heart Failure Caregiver Questionnaire had a mean of 46.8 ± 24.9 ; the physical well-being subscale had a mean of 44.4 ± 27.9 indicating the distress was lower in this subscale, emotional well-being had a mean of 53.3 ± 22.9 and the lifestyle subscale had 46.9 ± 28.1 . This indicates that the largest negative impact of caregiving is on the emotional well-being.

There was a significant difference between the countries, with carers in the United Kingdom feeling significantly more affected by caregiving than carers in the other three countries, Table 2. The same difference between the United Kingdom and the other countries was also found in all three subscales, Table 2.

**Caregiver Questionnaire: Higher scores indicate larger effect of caregiving on carers' lives, Ladder of Life; a higher score indicates better quality of life in the carer, Preparedness of caring: Higher score indicate better preparedness for being a carer,*

INSTRUMENTS	Australia	Canada	UK	US	Theoretical Range
Ladder of Life	6.3	6.5	5.0	6.4	0-10
Preparedness of Caring	15.9	15.9	13.6	16.9	0-32
Heart Failure Caregiver Questionnaire					
Total Score	39.2	39.8	57.9	45.8	0-100
Physical Well-being Subscale	37.4	35.0	56.2	43.4	0-100
Emotional Well-being Subscale	44.9	46.3	58.9	50.4	0-100
Lifestyle Subscale	39.2	39.9	58.3	44.1	0-100

A linear regression explaining 60% of how much the carer was affected by caregiving showed that perceived control over the heart disease, quality of life if the person with heart failure they cared for had been hospitalized and if caregiving had affected their health.

The distribution of the answering alternatives for the individual items in the questionnaire is in **Figures 14-17**.

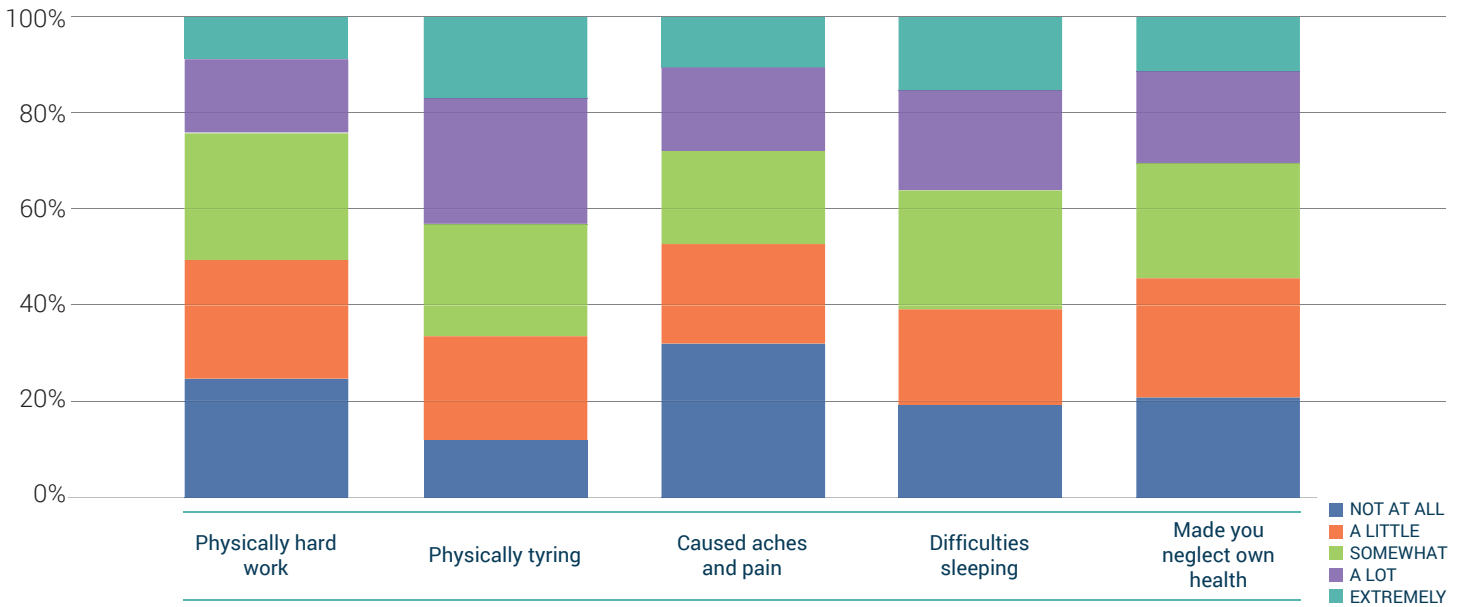


Figure 14. HF-CQ Physical Well-being subscale, describing how much caregiving has affected the carer during the past 4 weeks

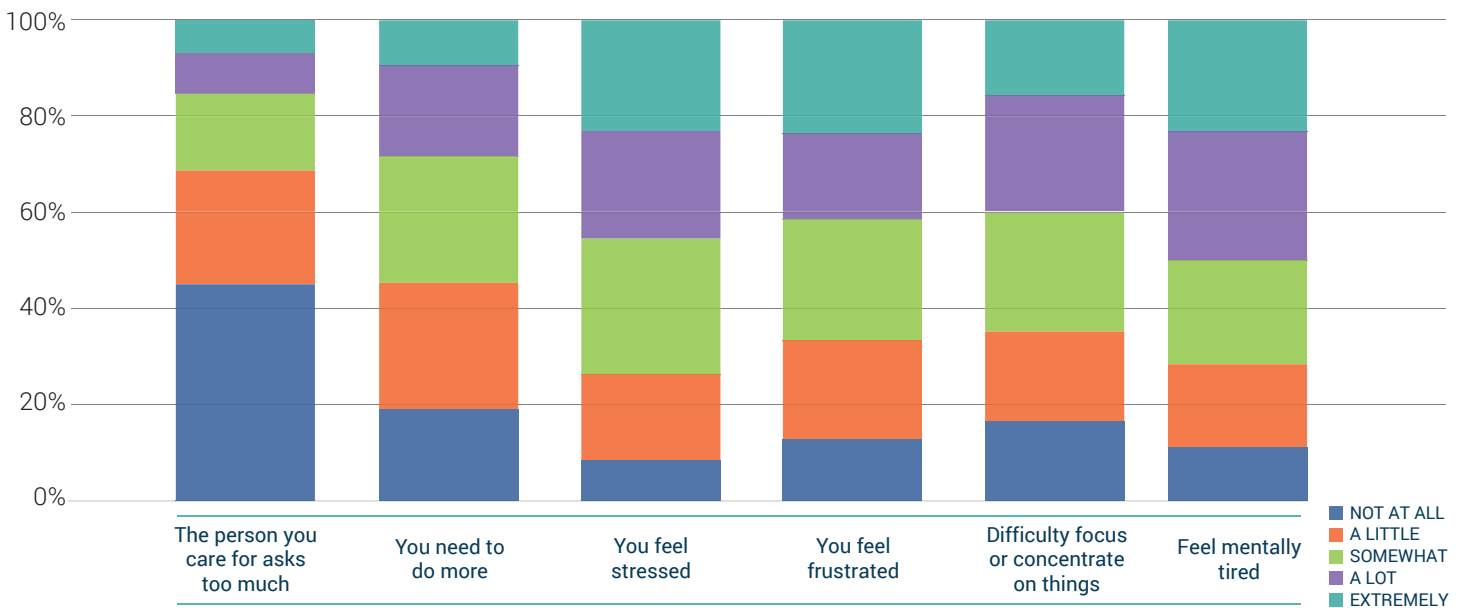


Figure 15. HF-CQ Emotional Well-being subscale, describing how much caregiving has affected the carer during the past 4 weeks

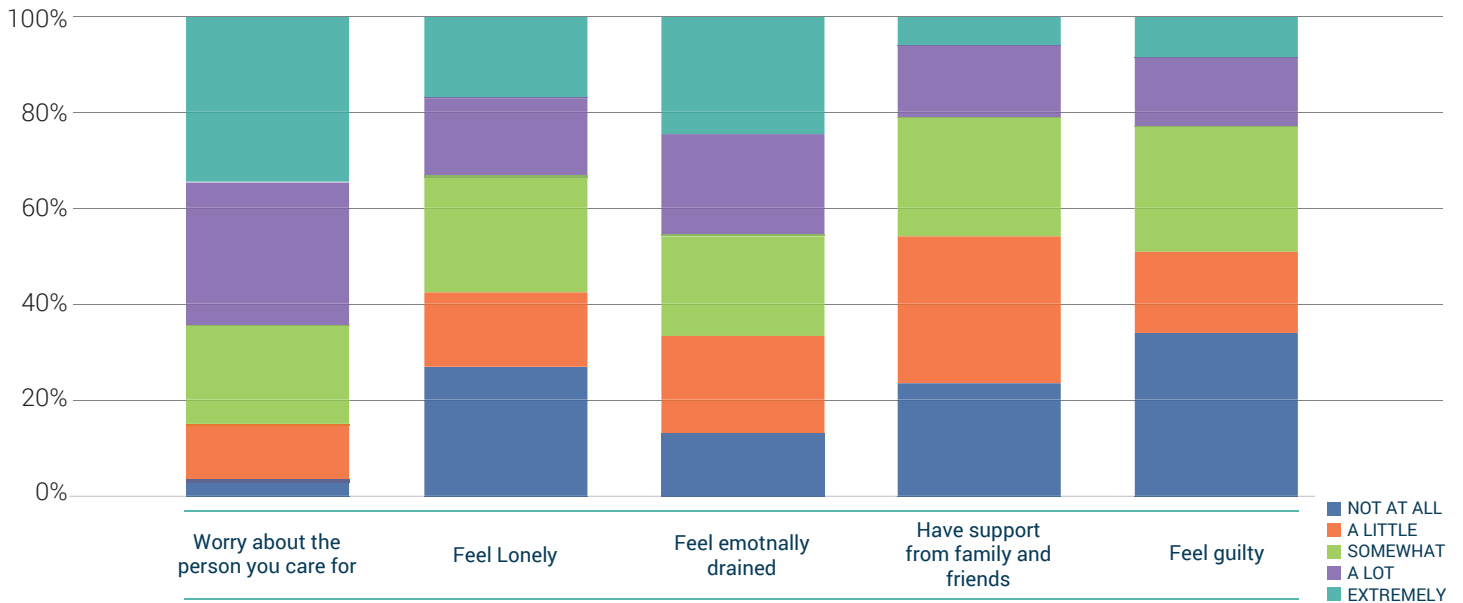


Figure 16. HF-CQ Emotional Well-being subscale, describing how much caregiving has affected the carer during the past 4 weeks

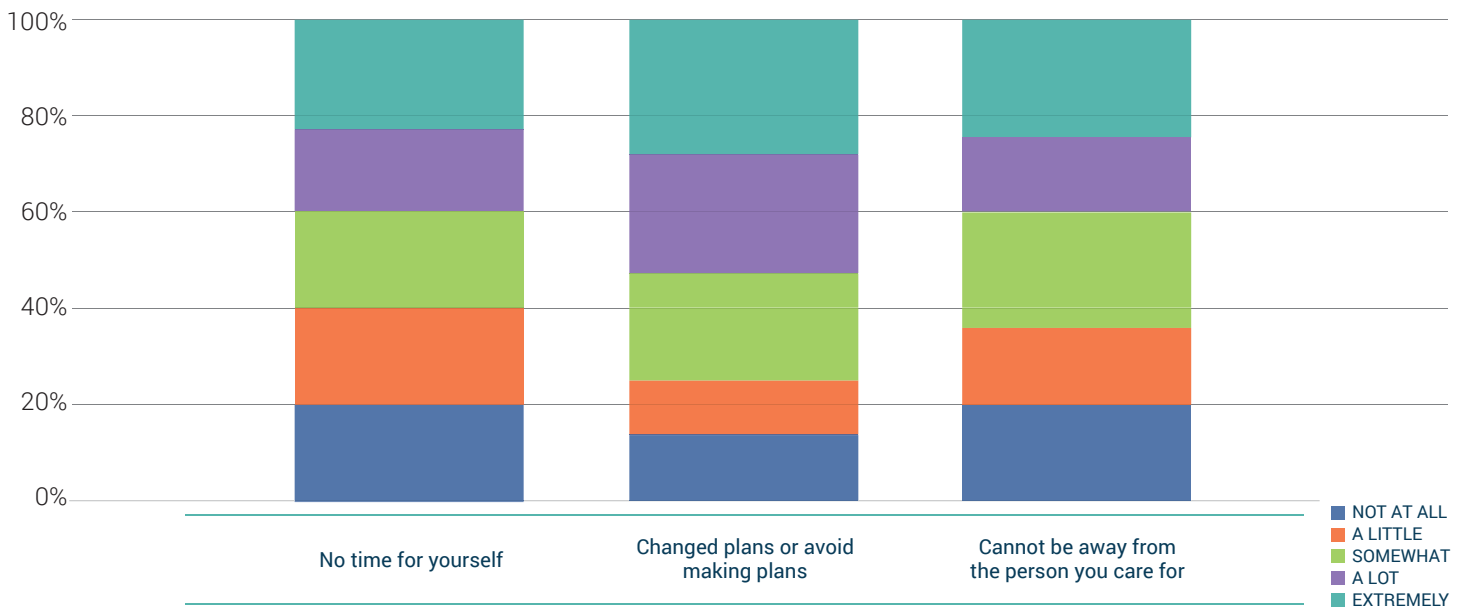


Figure 17. HF-CQ Lifestyle subscale, describing how much caregiving has affected the carer during the past 4 weeks

Working Situation of the Carers

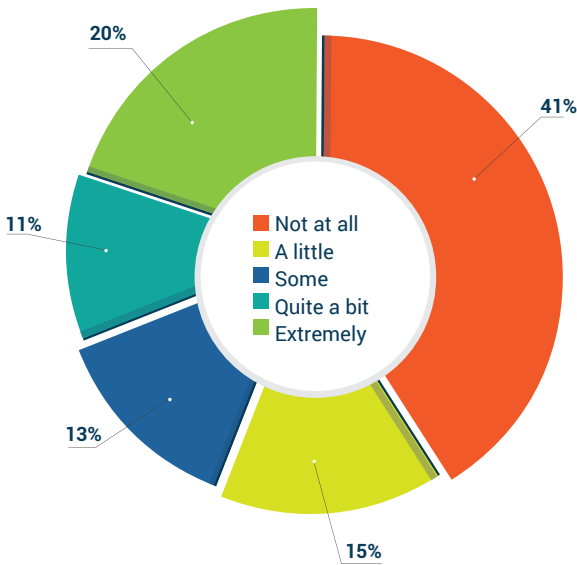


Figure 18. How much has caregiving made it difficult to do paid work?

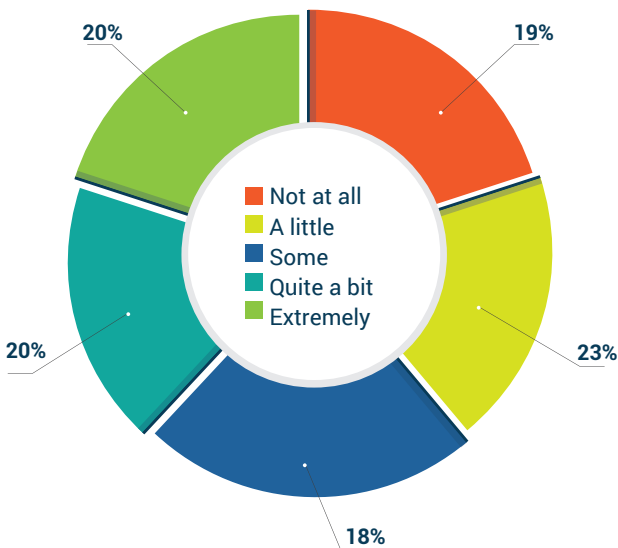


Figure 19. How much has caregiving affected you financially?

Almost one third (30%) of the carers worked full time, and 15% worked part time. Two-thirds of the carers (66%) stated that they had never had to leave a job due to caregiving. But for one-third, working life was clearly affected by caregiving tasks and they had to leave a job since they needed more time off to provide care (23%), could not afford paid help (5%), their job did not allow flexible hours (3%) or did not allow paid time off (3%). **Figure 18** showed how much caregiving made it difficult to do paid work. Half of the carers (50%) that worked had flexible work hours, and 30% could work remotely. More than two thirds (70%) had the option to go to work late, leave early or take some day off during the day.

Fifty percent had taken a leave of absence due to caregiving. One out of four caregivers (27%) stated that they could take paid leave. A majority (55%) could take unpaid leave. Thirty percent had carer support at work. Very few had access to emergency substitute care (6%) or carer support groups (7%).

Thirteen percent of the carers stated that they had to give up work entirely due to caregiving, 9% had turned down a promotion, 9% had lost job benefits, and 7% had received a warning about performance or attendance at work.

About one-third of the carers (30%) were retired, and 9% stated that they had retired early due to carer responsibilities. **Figure 19** shows that there was quite a diversity in how much caregiving had affected the carers financial situation equally distributed on a continuum from extremely to not at all.

Voices from Carers Struggling to Combine Work and Caregiving

There was an open-ended question in the survey where many of the carers wrote personal statements about how they struggled to combine work and caregiving. The carers described how they had to take an early retirement or quit their jobs leaving long careers to manage caregiving. For some, it was their own decision since they did not want to be away from home too much.

Some carers were pressured to quit or even fired due to little understanding for their carer situation from their employers. Other carers stated that they had changed jobs, decreased working hours or become self-employed to manage the caregiving situation. One man stated, "I work from home, but have had to cut my hours and so my income." Some of the caring sons and daughters had to move and change their city, province or state to be closer to their parent with heart failure and that also meant looking for a new job or stop working. One woman described her situation like this: "I have moved between states to care for multiple members of my family, and previous employers I have had wouldn't even let me have my phone on at work so I could answer receptive calls to check emergencies. The employers would not let me take time off to travel interstate to care for my family with heart failure, which is why I am forced to work casual jobs that have people who will cover me at short notice."

Carers stated that they struggled to manage work and also wanted to stop working to have more time for caregiving, but could not manage financially. One wife wanted to work, but her husband needed to give up work due to his heart failure and he would not do that unless the wife stopped working too. Another wife had an ultimatum from her boss: "divorce or quit this job." One man stated he had to leave a successful job in business since he frequently did not turn up at work due to caregiving tasks. Another carer said that "I don't get offered much work anymore because I sometimes can't turn up." Carers stated they struggled to maintain working due to their caring responsibilities. One carer described that she had retired early to live abroad, but had had to come back to the United Kingdom to be a carer. Due to restrictions of being a carer, she could not apply for work.

Several carers stated they were not given any sympathy or expected time off to deal with caregiving issues. Some carers stated they had to use all annual leave to cover time off for caregiving since their employers did not allow time off. Even when an employer was somewhat understanding and supportive, the carer still felt pressured, "I was allowed time off when I worked, but was made to feel like I was being a nuisance." Some carers developed health problems, mental and/or physical, and had to stop working due to the burden from caring in combination with their own health problems.



Conclusions and Policy Recommendations

The survey findings demonstrated that there were many similarities in the experiences of carers of persons with heart failure in the four countries that participated in the study. Since the survey used a convenience sample and there were demographic differences between the countries, the differences found should be interpreted with caution.

The importance of carers and social support in heart failure self-care, as well as carers' under-representation in current self-care programs, have been identified in the research literature. Carers play a vital role in assisting with the implementation and adherence to the treatment regime and self-care for persons with heart failure. Greater involvement by others like family and friends, besides the person with heart failure, has been found to improve self-care significantly; in fact, increased self-care in persons with heart failure can prolong survival significantly.

It is therefore noteworthy that this survey found that many carers felt unprepared for many of their caregiving tasks and not in control of the patient's heart failure condition. Carers need more education and skill building training as well as psychosocial support to increase preparedness for caring and perceived control over the heart disease. That can both improve carers life situation and well-being as well as give them tools to support their loved ones with heart failure to improve and maintain self-care behavior, such as adherence to medical treatment, exercise training, routine self-monitoring and symptom management when needed.

Carers are close to their loved ones with heart failure and provide a lot of both practical, emotional, nursing and medical care for the persons with heart failure during a substantial amount of time every week.

Only a minority felt supported by someone to balance their own well-being, and for many employed carers, their work and their health situation are adversely affected.

Based on the findings of this survey, we make the following recommendations

What can health care professionals do?

- Engage carers as an essential member of the heart failure team and acknowledge their critical role in the implementation of the treatment plan for persons with heart failure.
- Integrate a routine caregiver assessment into existing assessment processes and facilitate specific and targeted support to prevent physical and psychosocial health decline in carers.
- Support carers in navigating the system and helping them to gain access to existing services and supports. This includes carers' need for education about the heart failure condition, its treatment and the importance of self-care and psychosocial support.

What can governments and healthcare system decision-makers do?

- Examine the structure and viability of a navigation/information system to ensure caregivers know about and can easily access services and information when and as they are needed.
- Develop and test user-friendly technology in the home setting to support patients' and caregivers' needs, especially in the case of distance caregiving.
- Enhance data collection and research to inform the development of evidence-based policies and programs for carers, particularly among vulnerable and underserved populations.
- Develop policy measures that will not only reduce the financial burden of caregiving but also help protect future income for those who need to leave their jobs on a temporary or permanent basis because of caregiving responsibilities.
- Ensure fairness and affordability by integrating health and economic impact of caregiving into the cost-benefit analysis of health interventions and programs of support.
- Implement incentives for employers to include support for working caregivers in their human resource strategies.

What can private, voluntary organizations and community associations do?

- Improve awareness and understanding of the role and impact of caregiving by recognizing caregivers in their awareness and advocacy campaigns.
- Promote evidence-based tools and resources to facilitate physicians, clinicians and care providers in recognizing and supporting the patient-caregiver dyad.
- Invest in education, training, and skills development initiatives to better prepare carers for their caring role.
- Develop programs of work targeted at employers to encourage greater understanding of the challenges facing carers juggling work and care and various supports they can provide.
- Provide flexible health and support services to enable carers to be able to juggle aspects of their lives.

What can carers do?

- Be actively involved in decision-making and have a care conversation with the person you are supporting and members of their health care team to understand your role in their clinical care and future well-being.
- Be your own advocate and learn how to support your health and well-being. Learn signs of caregiver stress and find out what supports are available for you.
- Understand short, medium and long-term care options, and support persons with heart failure in following the directions of their healthcare providers regarding medication and lifestyle changes.



References

1. Yancy CW, Jessup M, Bozkurt B, Butler J, Casey DE Jr, Colvin MM, Drazner MH, Filippatos GS, Fonarow GC, Givertz MM, Hollenberg SM, Lindenfeld J, Masoudi FA, McBride PE, Peterson PN, Stevenson LW, Westlake C. 2017 ACC/AHA/HFSA Focused Update of the 2013 ACCF/AHA Guideline for the Management of Heart Failure: A Report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines and the Heart Failure Society of America. *Circulation*. 2017 Apr 28. [Epub ahead of print]
2. Ponikowski P, Voors AA, Anker SD, et al. 2016 ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure: The Task Force for the diagnosis and treatment of acute and chronic heart failure of the European Society of Cardiology (ESC) Developed with the special contribution of the Heart Failure Association (HFA) of the ESC. *Eur Heart J*. 2016;37(27):2129-2200.
3. Howlett JG, Chan M, Ezekowitz JA, Harkness K, Heckman GA, Kouz S, Leblanc MH, Moe GW, O'Meara E, Abrams H, Ducharme A, Grzeslo A, Hamilton PG, Koshman SL, Lepage S, McDonald M, McKelvie R, Rajda M, Swiggum E, Virani S, Zieroth S; The Canadian Cardiovascular Society Heart Failure Companion: Bridging Guidelines to Your Practice. *Can J Cardiol*. 2016 Mar;32(3):296-310
4. Lainscak M, Blue L, Clark A, Dahlström U, Dickstein K, Ekman I, et al. Self-care management of heart failure: practical recommendations from the Patient Care Committee of the Heart Failure Association of the European Society of Cardiology. *European Journal of Heart Failure* 2011;13, 115–26.
5. Clark A, Reid M, Morrison C, Capewell, S, Murdoch D, McMurray J. The complex nature of informal care in home-based heart failure management. *Journal of Advanced Nursing* 2008;61; 373–83.
6. Dionne-Odom N, Hooker SA, Bekelman D, Ejem D, McGhan G, Kitko L, Strömberg A, Wells R, Astin M, Metin ZG, Mancarella G, Pamboukian SV, Evangelista L, Buck HG, Bakitas MA, IMPACT-HF National Workgroup. Family caregiving for persons with heart failure at the intersection of heart failure and palliative care: a state-of-the-science review. *Heart Fail Rev*. 2017 Feb 4. [Epub ahead of print]

7. Stamp K, Dunbar S, Clark P, Reilly C, Gary R, Higgins M et al. Family Context Influences Psychological Outcomes of Depressive Symptoms and Emotional Quality of Life in Patients With Heart Failure. *The Journal of Cardiovascular Nursing* 2014;29; 517–27.
8. Hoskins L, Walton-Moss B, Clark H, Schroeder M, Thiel L. Predictors of hospital readmission among the elderly with congestive heart failure. *Home Healthcare Nurse* 1999; 17; 373–81.
9. Chin M, Goldman L. Correlates of early hospital readmission or death in patients with congestive heart failure. *The American Journal of Cardiology* 1997; 79; 1640–4.
10. Chung M, Mosor D, Lennie T, Frazier S. Perceived social support predicted quality of life in patients with heart failure, but the effect is mediated by depressive symptoms. *Quality of Life Research* 2013; 22; 1555–63.
11. Chung M, Lennie T, Riegel B, Wu J-R, Dekker R, Moser D. Marital status is an Independent Predictor of Event-Free Survival of Patients with Heart Failure. *American Journal of Critical Care* 2009; 18; 562.
12. Mårtensson, J., Dracup, K., Canary, C., Fridlund, B. Living with heart failure: depression and quality of life in patients and spouses. *J Heart Lung Transplant* 2003;22: 460–7.
13. Pihl E, Jacobsson A, Fridlund, B, Strömberg A, Mårtensson J. Depression and health-related quality of life in elderly patients suffering from heart failure and their spouses: a comparative study. *European Journal of Heart Failure* 2005; 7: 583–9.
14. Chung M, Pressler S, Dunbar S, Lennie, T, Moser, D. Predictors of Depressive Symptoms in Caregivers of Patients With Heart Failure. *The Journal of Cardiovascular Nursing* 2010; 25: 411–9.
15. Saunders M. Factors associated with caregiver burden in heart failure family caregivers. *Western Journal of Nursing Research* 2008;30: 943–59.
16. Pressler SJ, Gradus-Pizlo I, Chubinski SD, Smith G, Wheeler S, Wu, J et al. Family caregiver outcomes in heart failure. *American Journal of Critical Care* 2009; 18: 149–59.
17. Bahrami M, Etemadifar S, Shahriari M, Farsani, AK. Informational needs and related problems of family caregivers of heart failure patients: A qualitative study. *Journal of Education and Health Promotion* 2014; 3: 113.
18. Clark A, Freyberg C, McAlister F, Tsuyuki, R, Armstrong P, Strain L. Patient and informal caregivers' knowledge of heart failure: necessary but insufficient for effective self-care. *European Journal of Heart Failure* 2009;11: 617–21.
19. Joo H, Zhang P, Wang G. Cost of informal care for patients with cardiovascular disease or diabetes: current evidence and research challenges. *Qual Life Res.* 2017;26(6):1379-1386.
20. Strömberg A, Luttik ML. Burden of caring: risks and consequences imposed on caregivers of those living and dying with advanced heart failure. *Curr Opin Support Palliat Care.* 2015;9(1):26-30.

21. Jonkman NH, Westland H, Groenwold RH, et al. Do self-management interventions work in patients with heart failure? An individual patient data meta-analysis. *Circulation*. 2016;115.018006.
22. Buck HG, Harkness K, Wion R, et al. Caregivers' contributions to heart failure self-care: A systematic review. *European Journal of Cardiovascular Nursing* 2015;14(1):79-89.
23. Humphrey L, Kulich K, Deschaseaux C, Blackburn S, Maguire L, Stromberg A. The Caregiver Burden Questionnaire for Heart Failure (CBQ-HF): face and content validity. *Health Qual Life Outcomes* 2013, 11(1):84.
24. Strömberg A, Bonner N, Grant L, Bennett B, Chung ML, Jaarsma T, Luttik ML, Lewis EF, Calado F, Deschaseaux C. Psychometric Validation of the Heart Failure Caregiver Questionnaire (HF-CQ®). *Patient*. 2017 Mar 25. [Epub ahead of print]
25. Cantril H. *The pattern of human concerns*. New Brunswick, NJ: Rutgers university 1965.
26. Archbold et al. Mutuality and preparedness of caregiver role strain. *Research in Nursing and Health* 1990;13:375-384.

Appendix A

Heart failure questionnaire

Four nation study of carers of persons with heart failure

Section A

Instructions to complete the survey

Thank you for taking time to complete this study. It is a study conducted in four countries: **Australia, Canada, United Kingdom and United States**, to understand the impacts on caring for adults suffering from chronic heart failure. Your responses will be very valuable and will help us to advocate the type of information, advice and support that is needed for carers of people with heart failure.

The definition of a carer in this survey is an individual that provides unpaid care to support a relative or friend, 18 years or older, who is diagnosed with heart failure. This may include helping with personal needs, household chores, assisting with medical or nursing tasks, managing finances and arranging for outside services. Around the world, the term carer is used interchangeably with caregiver or family caregiver.

This is a one-time survey and should take approximately 10-15 minutes to complete.

Section A

This section includes questions about yourself.

1. Country where you live:

- Australia
- Canada
- UK
- US

Four nation study of carers of persons with heart failure

United Kingdom

2. In which nation do you reside?

- England
- Wales
- Scotland
- Northern Ireland

3. Ethnic or racial group with whom you most identify

- White: English/Welsh/Scottish/Northern Irish/British
- White: Irish
- White: Gypsy or Irish Traveller
- White: any other white background
- Mixed/multiple ethnic groups: White and Black Caribbean
- Mixed/multiple ethnic groups: White and Black African
- Mixed/multiple ethnic groups: White and Asian
- Asian/Asian British: Indian
- Asian/Asian British: Pakistani
- Asian/Asian British: Bangladeshi
- Asian/Asian British: Chinese
- Black/Black British: African
- Any other Black/African/Caribbean background (please specify below)
- Arab
- Other ethnic group (please specify below)
- Any other Mixed/multiple ethnic background (please specify below)

Four nation study of carers of persons with heart failure

Canada

4. In which province/territory do you reside?

- Newfoundland and Labrador
- Prince Edward Island
- Nova Scotia
- New Brunswick
- Quebec
- Ontario
- Manitoba
- Saskatchewan
- Alberta
- British Columbia
- Yukon
- Northwest Territories
- Nunavut

5. With which ethnic or racial group do you most identify?

- Aboriginal (First Nations, Inuit, Métis)
- Black or African/Caribbean
- Latin American
- Filipino
- Arab
- Asian
- Southeast Asian / West Asian (Middle East and the Near East)
- Korean
- Japanese
- Chinese
- Pacific Islander
- European
- Caucasian (white)
- Other (please specify)

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Australia

6. With which ethnic or racial group do you most identify?

- Aboriginal/Torres Strait Islander
- Australian
- Other

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United States

7. With which ethnic or racial group do you most identify?

- Non-hispanic White
- Hispanic
- Black or African American
- American Indian or Alaska Native
- Asian
- Native Hawaiian/Pacific Islander
- Other (please specify)

Four nation study of carers of persons with heart failure

Section A - continued

8. Your age:

9. Your gender:

- Man
- Woman
- Transgendered
- Prefer not to answer

10. Your employment status:

- Working full time
- Working part time
- Full-time caring for home and family
- Retired
- Student
- Not currently working
- Other

11. Your educational level:

- Less than secondary/high school graduate
- Secondary/high school graduate
- College/university educated

12. Are you the primary carer for a person with heart failure?

- No
- Yes

13. For how long have you been a carer of this person with heart failure?

- Less than 1 year
- 1-2 years
- More than 2 years but less than 5 years
- More than 5 years
- Do not know

Four nation study of carers of persons with heart failure

Section B

This section includes questions about the person with heart failure that you care for.

14. What is your relationship to the person with heart failure for whom you provide care?

I am the:

- Husband/wife/partner/companion
- Daughter/son/fosterchild
- Granddaughter/grandson
- Sister/sister-in-law
- Brother/brother-in-law
- Mother/father
- Grandmother/grandfather
- Friend
- Neighbor
- Other (please specify)

15. Age of the person with heart failure that you care for:

16. How long ago was the person you care for diagnosed with heart failure?

- Less than 1 year
- 1-2 years
- More than 2 years but less than 5 years
- More than 5 years
- Do not know

17. Does the person with heart failure that you care for also have other health conditions? *It is possible to select more than one condition.*

- No other condition
- Alzheimer, dementia
- Stroke
- Kidney disease
- Lung disease
- Diabetes
- Depression
- Anemia
- Cancer
- Musculoskeletal problems, arthritis
- Obesity
- High blood pressure
- Not sure
- Other (please specify)

18. Where does the person you care for live?

- In your household
- Within twenty minutes of your home
- Between twenty minutes and an hour from your home
- One to two hours from your home
- More than two hours away?

19. Has the person with heart failure that you care for been hospitalized for heart failure within the last year?

- Never
- 1-2 times
- Frequently (more than 2 times)

Four nation study of carers of persons with heart failure

Section C

This section includes questions related to your caring situation.

20. On average, how often do you visit the person you care for?

- We live together
- More than once a week
- Once a week
- Few times a month
- Once a month
- Few times a year

21. Do you help the person you care for with any of these tasks?

	No	Yes
Getting in and out of beds and chairs	<input type="radio"/>	<input type="radio"/>
Getting dressed	<input type="radio"/>	<input type="radio"/>
Getting to and from the toilet	<input type="radio"/>	<input type="radio"/>
Bathing or showering	<input type="radio"/>	<input type="radio"/>
By dealing with incontinence	<input type="radio"/>	<input type="radio"/>
By feeding him or her	<input type="radio"/>	<input type="radio"/>
Managing finances, such as paying bills or filling out insurance claims	<input type="radio"/>	<input type="radio"/>
Grocery or other shopping	<input type="radio"/>	<input type="radio"/>
Housework, such as doing dishes, laundry, or straightening up	<input type="radio"/>	<input type="radio"/>
Preparing meals	<input type="radio"/>	<input type="radio"/>
Transportation, either by driving him/her, or helping him/her get transportation	<input type="radio"/>	<input type="radio"/>
Arranging outside services, such as nurses, home care aides, physiotherapy or meals-on-wheels	<input type="radio"/>	<input type="radio"/>
Supervision with tasks, reminding to do things, coaching to provide support	<input type="radio"/>	<input type="radio"/>

Four nation study of carers of persons with heart failure

Section C continued

22. Overall, how difficult is it for you to help with these tasks?

- Not at all difficult
- Not too difficult
- Somewhat difficult
- Pretty difficult
- Very difficult

23. **Do you help the person with heart failure you care for with any medical/nursing tasks?**

This might include preparing or giving medications like pills, eye drops, or injections, preparing food for special diets, or wound care. You could be monitoring things like weight, symptoms, blood pressure or blood sugar, helping with incontinence, or operating equipment like hospital beds, wheelchairs, oxygen tanks or nebulizers.

- No
- Yes

24. Overall, how difficult is it for you to help with these tasks?

- Not at all difficult
- Not too difficult
- Somewhat difficult
- Pretty difficult
- Very difficult

25. Did anyone prepare you to do these tasks?

This might include preparing or giving medications like pills, eye drops, or injections, preparing food for special diets, or wound care. You could be monitoring things like weight, symptoms, blood pressure or blood sugar, helping with incontinence, or operating equipment like hospital beds, wheelchairs, oxygen tanks or nebulizers.

- No
- Yes

26. How prepared do you feel to take on these medical/nursing tasks?

- Not at all well prepared
- Not too well prepared
- Somewhat well prepared
- Pretty well prepared
- Very well prepared

27. Thinking now of all the kinds of help you provide for the person with heart failure you care for, about how many hours do you spend in an average week, helping?

- Less than one hour per week
- The person requires constant care
- Average hours per week (enter digits)

28. Did you have a choice in becoming a carer?

- No
- Yes

29. How much control do you feel that you have as a carer over the heart failure condition that the person you care for have?

- None at all
- Not much control
- Some control
- Pretty good control
- Very good control

30. Has anyone supported you in balancing your own well-being while being a carer?

- No
- Yes

31. The following questions deal with how prepared you feel for caring for your relative/friend with heart failure.

How well prepared do you think you are....

	Not at all well prepared	Not too well prepared	Somewhat well prepared	Pretty well prepared	Very well prepared
to take care of your relative/friend's physical needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
to take care of your relative/friend's emotional needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
to find out about and set up services for your relative/friend?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
in responding to the stress of caregiving?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
to make caregiving activities pleasant for both you and your relative/friend?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
to respond to and handle emergencies that involve your relative/friend?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
to get the help and information you need from the health care system?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Overall, how well prepared do you think you are to care for your relative/friend?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Four nation study of carers of persons with heart failure

SECTION D

This section includes questions about how caring affects your well-being.

32. How would you describe your own health?

- Poor
- Fair
- Good
- Very good
- Excellent

33. Would you say being a caregiver has affected your health?

- Made it worse
- Not affected it
- Made it better

34. On a scale of 1 to 10, with 1 being the worst possible quality of life, and 10 being the best possible quality of life, where are you now?

worst possible quality of life	2	3	4	5	6	7	8	9	best possible quality of life
★	★	★	★	★	★	★	★	★	★

35. How would you currently describe the relationship between you and the person that you care for?

Poor	2	3	4	5	6	7	8	9	Excellent
★	★	★	★	★	★	★	★	★	★

36. How has caregiving for a person with heart failure affected you during the last 4 weeks?

During the past 4 weeks, how much...

	Not at all	A little	Somewhat	A lot	Extremely
has caregiving been physically hard work?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
has caregiving made you feel physically tired?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
has caregiving caused you aches and pains?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
has caregiving made it difficult to sleep?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
has caregiving made you neglect your own health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
have you felt the person you care for asks too much of you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
have you felt like you need to do more for the person you care for?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
has caregiving made you feel stressed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
has caregiving made you feel frustrated?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
has caregiving made it difficult to focus or concentrate on other things?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
has caregiving made you feel mentally tired?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
has caregiving made you worry about the person you care for?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
has caregiving made you feel lonely?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
has caregiving made you feel emotionally drained?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
how much support have you had from family or friends?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
have you felt guilty because the time you spent caregiving limited what you can do for others?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
have you felt like you have no time for yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
has caregiving caused you to change your plans or made you avoid making plans?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
have you felt you cannot be away from the person you care for?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

37. During the past 4 weeks, has caregiving made it difficult to do paid work?

- Not at all
 A little
 Somewhat
 A lot
 Extremely

38. Does your employer offer any of the following?

	No	Yes
Flexible work hours	<input type="radio"/>	<input type="radio"/>
Working remotely	<input type="radio"/>	<input type="radio"/>
Programs like information, referrals, counseling, or an employee assistance program, to help carers like yourself	<input type="radio"/>	<input type="radio"/>
Paid leave, where you could take paid time off from work for several weeks to care for a family member	<input type="radio"/>	<input type="radio"/>
Unpaid leave	<input type="radio"/>	<input type="radio"/>
Emergency substitute care	<input type="radio"/>	<input type="radio"/>
Staff carer support group	<input type="radio"/>	<input type="radio"/>

39. As a result of caregiving, did you ever experience any of these things at work?

	No	Yes
Went in late, left early, or took time off during the day to provide care	<input type="radio"/>	<input type="radio"/>
Took a leave of absence	<input type="radio"/>	<input type="radio"/>
Went from working full-time to part-time, or cut back your hours	<input type="radio"/>	<input type="radio"/>
Turned down a promotion	<input type="radio"/>	<input type="radio"/>
Lost any of your job benefits	<input type="radio"/>	<input type="radio"/>
Gave up working entirely	<input type="radio"/>	<input type="radio"/>
Retired early	<input type="radio"/>	<input type="radio"/>
Received a warning about your performance or attendance at work	<input type="radio"/>	<input type="radio"/>

40. As a result of caregiving, did you have to leave your job?

- No
- Needed more time to provide care for the person with heart failure I care for
- Could not afford paid help for the person with heart failure I care for
- Job did not allow flexible work hours
- Job did not allow time off with pay
- Other (please specify)

41. Has caregiving affected you financially?

- Not at all
- A little
- Some
- Quite a bit
- Extremely

42. Overall, has caring had potential benefits for you?

- Not at all
- A little
- Some
- Quite a bit
- A great deal

Appendix B: Nation-Specific Data

Australia



Heart Failure Carers, Australia (IACO Study Sample)

Age (mean)	57.6
Gender (%)	
Men	35 (25%)
Women	103 (75%)
Ethnic/Racial group (%)	
Aboriginal/Torres Islander	11 (8%)
Australian	123 (90%)
Other	3 (2%)

¹ Total Population of Australia (2017):
24.6 million

² Total Number of Carers in Australia:
2.7 million

³ Annual Economic Value of Their Care: **\$60.3 billion AUD**

⁴ Percent of Employed Carers in Australia: **66%**

Australia at a Glance

Age (median)	38
Gender (%)	
Men	11.5m (49.3%)
Women	11.8m (50.7%)
Ethnicity/race (%)	
Aboriginal and/or Torres Strait Islanders	650,000 (2.8%)
Both parents born overseas	8m (34.4%)
One parent born overseas	2.5m (11.1%)
Both parents born in Australia	11m (47.3%)

Data from the 2016 Australian Bureau of Statistics Census of Population and Housing. Data may not add up to exactly 100% because some people failed to answer all the questions.

¹ Australian Bureau of Statistics Census of Population and Housing, 2016

² Australian Bureau of Statistics Survey of Ageing, Disability and Carers (SDAC), 2015

³ Deloitte Access Economics, The Economic Value of Informal Care in Australia in 2015, 2015

⁴ Australian Bureau of Statistics Survey of Ageing, Disability and Carers (SDAC), 2015

Number of Adults in Australia with heart failure:

300,000 with 30,000 new cases diagnosed each year ⁵

Heart failure hospital readmissions or death:

Among people admitted to hospital with heart failure, approximately 25-30% are readmitted or die within 30 days of discharge. ⁶

Estimated Cost to Australia from Heart Failure:

Hospitalisation due to heart failure in Australia was estimated to cost \$840 million (AU), leading to a total direct cost of >\$1billion (AU). This estimate was based on a model that considered the cost per patient and the estimated incidence of heart failure. ⁷

⁵ Australian Institute of Health and Welfare and the National Heart Foundation of Australia. *Heart, stroke and vascular diseases – Australian facts 2011*. Canberra: National Centre for Monitoring Cardiovascular Disease, 2011

⁶ *The Change of Heart Report, Time to End Cardiovascular Complacency*. Baker IDI Heart and Diabetes Institute; 2016

⁷ National Heart Foundation of Australia. *A systematic approach to chronic heart failure care: a consensus statement*. Melbourne. National Heart Foundation of Australia, 2013

Australian Recommendations:

From the Change of Heart Report by Baker IDI

- Develop a national strategy to reduce hospital admissions
- Establish uniform criteria for disease management programs
- Access to new drugs such as the new combination angiotensin receptor blocker/neprolysin inhibitor
- Ensure that people hospitalized with heart failure leave the hospital with a nurse-led, multidisciplinary disease management plan to minimise the risk of readmission, especially for those identified as being high risk.
- Encourage 24-hour blood pressure management

From the National Heart Foundation

- People with chronic heart failure should be educated about lifestyle changes (e.g. increase physical activity levels, reduce salt intake, symptoms and how to manage fluid load and weight). They should also be supported to make these changes, including a management plan and routine psychosocial assessment.
- All patients hospitalized for heart failure should have post discharge access to best-practice multidisciplinary CHF care. This ensures that clinical problems are detected and addressed proactively to manage the disease. This also ensures that patients or carers can control and manage symptoms, medications are titrated as required, patients undertake exercise training, and a pharmacy review is conducted. Care may consist of home visits, phone follow-up, clinic visits and telehealth. Every service has a medical sponsor who is either a cardiologist or general physician
- Multidisciplinary chronic heart failure care is distinguishable from generic chronic disease management programs by the special needs of patients with chronic heart failure such as ongoing medicines titration, symptom monitoring and management of devices. This necessitates specialized evidence-based treatment strategies associated with optimal outcomes. Accordingly, effective chronic heart failure care often requires access to specialized knowledge and expertise

Heart Support – Australia Recommendations

- Increase awareness and access to support programs providing psycho-social support post cardiac rehab programs
- The development of monitored and staged return to exercise programs
- Further research into the incidences of CHF in indigenous Australians
- Better screening in routine medical assessments for early diagnosis at the GP level

Canada



Heart Failure Carers, Canada (IACO Study Sample)

Age (mean)	57.9
Gender (%)	
Men	51 (21%)
Women	185 (77%)
Prefer not to answer	4 (2%)
Province/Territory (%)	
Newfoundland and Labrador	11 (4.5%)
Nova Scotia	15 (6%)
New Brunswick	11 (4.5%)
Quebec	8 (3%)
Ontario	99 (41%)
Manitoba	12 (5%)
Saskatchewan	8 (3%)
Alberta	28 (12%)
British Columbia	49 (20%)
Yukon	1 (1%)
Ethnicity/race (%)	
Aboriginal (First Nation, Inuit, Métis)	5 (2%)
Black or African/Caribbean	1 (0.5%)
Filipino	4 (2%)
Asian	1 (0.5%)
Southeast Asian/West Asian (Middle East and the near Middle East)	6 (3%)
Korean	1 (0.5%)
Chinese	4 (2%)
Pacific Islander	2 (1%)
European	19 (8%)
Caucasian (white)	196 (82%)

Heart failure is a significant health issue for hundreds of thousands of Canadians and their families, and its reach is expanding.

600,000

Canadians are living with heart failure

50,000

Canadians are diagnosed each year with Heart Failure

1 in 2

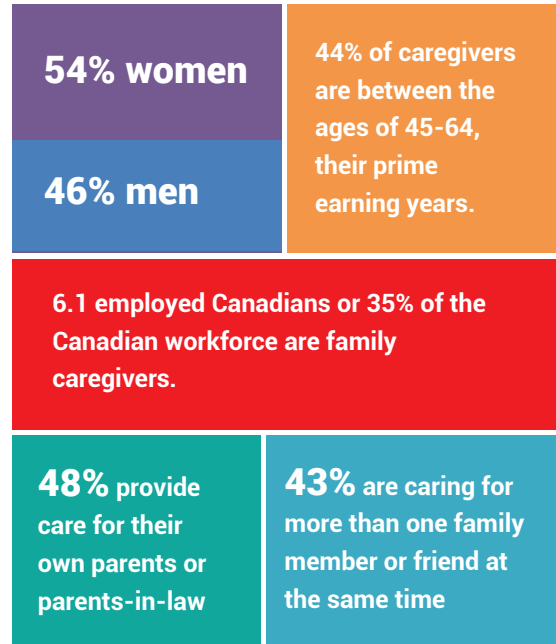
Canadians have been touched by heart failure – either diagnosed with it themselves or having a family member or close friend with the condition.

Heart failure costs more than **\$2.8 billion** per year.

The condition has the regrettable distinction of being a leading cause of hospitalization. Hospital visits due to heart failure have gone up every year for the past six years, with 60,000 reported in 2013-2014, a relative increase of 13%. If they are so sick that they

become hospitalized, the average length of stay for heart failure patients is long at eight days. Various sources estimate that 1 in every five heart failure patients find themselves back in the hospital within 30 days either for heart failure specifically (in about half of those cases) or another related cause.

There are 8.1 million Canadians who take on an unpaid caring role, with cardiovascular disease being one of the top common conditions requiring help from caregivers. In a population of 36 million, that is 1 in 4 Canadians.



Caregivers' dedication, selflessness, and compassion not only enhance the quality of life for the person they care for but also contribute to the sustainability of our health care system, economy, and society as a whole.



IMPROVING THE LIVES OF HEART FAILURE PATIENTS AND THEIR CAREGIVERS

Carers come from different backgrounds, different age demographics, and different income levels; there is no one size fits all. Despite this diversity, during consultations with carers and caregiver support groups across Canada, some common needs were identified. These universal priorities were incorporated into A Canadian Carer Strategy by Carers Canada, launched in 2008 and updated in 2014, to provide a framework for the development of legislation, policy, and programs that support the vital role of carers. These universal priorities are:

1. Safeguard the health and well-being of carers
2. Minimize excessive financial burden placed on carers
3. Improve access to carer support services and patient care resources
4. Create supportive workplaces and educational environments that respect carer obligations, and;
5. Invest in research on carers as a foundation for evidence-informed decision making.

All elements of society, including the public and private sectors, and individual Canadians, must work together to achieve the vision of “A Canada that recognizes, respects and supports the integral role of carers in society.”

What can healthcare providers do?

- Follow the Canadian Cardiovascular Society Heart Failure Management Guidelines.
- Improve early diagnosis for heart failure patients and access to appropriate treatment and care.
- Incorporate into their practice an assessment of caregivers’ risks, needs, strengths, and preferences.
- Improve patient and caregiver education around managing heart failure and self-care.

What can governments and healthcare system decision-makers do?

- Introduce/expand access to caregiver income benefits, such as amendment of the current tax credits to make them refundable.
- Extend the existing child rearing drop-out provisions of the Canada Pension Plan to cover caregiving responsibilities or making contributions to the Canada Pension Plan for employees who need to leave the workplace to provide unpaid caregiving.
- Explore a variety of funding options to increase access to flexible respite programs
- Improve, expand and coordinate services across the continuum of care from prevention to diagnosis, treatment, management, end-of-life planning and palliative care.
- Support research around the experience of carers including representation from vulnerable, racialized, underserved and Indigenous populations.

What can Canadians do?

- Patients and their caregivers should be actively involved in decision-making and management of heart failure.
- Engage in a discussion about treatment and management strategies with their health care providers. Patients and caregivers are encouraged to discuss and collaborate with healthcare providers regarding optimal ways to use medication and make lifestyle changes.
- Patient and their family caregivers can be their own best advocates to improve diagnosis, treatment, management, end-of-life planning and palliative care.

What the Heart and Stroke Foundation is doing:

- Funding research that will save more lives and improve the quality of life for heart failure patients.
- Developing patient education resources, available at www.heartandstroke.ca/heartfailure.

- Increasing public awareness of Heart Failure and the importance of accurate early diagnosis
- Developing innovative programs to support those living with heart failure.
- Advocating for healthy environments to help Canadians reduce their risk of heart disease.

What Carers Canada is doing:

- Building awareness of the value and needs of carers through national and international initiatives.
- Building strong relations with government stakeholders and advocating for carers' needs.
- Facilitate collaborative partnerships and engagements across Canada to leverage local activities and support the advancement of the Carer Strategy.

References:

- Carers Canada. 2017. A Canadian Carer Strategy. Available at: <http://www.carerscanada.ca/priorities/#caregiver-strategy>
- Heart & Stroke Foundation. 2016. The Burden of Heart Failure. Available at: <http://www.heartandstroke.ca/-/media/pdf-files/canada/2017-heart-month/heartandstroke-reportonhealth-2016.ashx?la=en>
- Hollander, J. M., Liu, G., & Chappell, N. 2009. Who Cares and How Much. *Healthcare Quarterly*, 12(2), 42-49.
- Fast, J., Lero.D., DeMarco, R., Ferreira, H., & Eales, J.2014. Combining Care Work and Paid Work: Is it Sustainable? University of Alberta: Research on Aging, Policies, and Practice.
- Statistics Canada. (2013). Portrait of caregivers, 2012. Catalogue no. 89-652 X- No.001. Ottawa, ON: Statistics Canada Social and Aboriginal Statistics Division

United Kingdom



Heart Failure Carers, United Kingdom (IACO Study Sample)

Age (mean)	60.8
Gender (%)	
Men	38 (8%)
Women	170 (81%)
Prefer not to answer	1 (1%)
Nation (%)	
England	161 (77 %)
Wales	19 (9 %)
Scotland	17 (8 %)
Northern Island	13 (6 %)
Ethnicity/race (%)	
White (English, Welsh, Scottish, Northern Irish, British)	192 (91%)
White (Irish)	5 (2%)
White (Gypsy or Irish Traveller)	0 (0%)
White (Other)	5 (2%)
Mixed/multiple ethnic group: White and Black Caribbean	0 (0%)
Mixed/multiple ethnic group: White and Black African	0 (0%)
Mixed/multiple ethnic group: White and Asian	0 (0%)
Asian/Asian British: Indian	1 (0.5%)
Asian/Asian British: Pakistani	1 (0.5%)
Asian/Asian British: Bangladeshi	2 (1%)
Asian/Asian British: Chinese	0 (0%)
Black/Black British: African	2 (1%)
Any other Black/African/Caribbean	2 (1%)
Arab	1 (0.5%)
Other	1 (0.5%)

Total population of the UK (2016):

65.64 million people

⁸ Total number of carers in the UK: **6.5 million**

⁹ Annual value of their care: **£132 billion a year** (ref: Valuing Carers, the rising value of carers' support S Yeandle and L Buckner, University of Sheffield and University of Leeds, published by Carers UK, 2015.

¹⁰ Percentage of carers in workplace: **70%**. **1 in every 9 employees** has caring responsibilities.

¹¹ Number of persons in the UK with heart failure: **900,000**

¹² Cost to UK society of heart failure: Nearly **2%** of the NHS budget. **5%** of all hospital admissions are heart failure related.

¹³ Carers are twice as likely to be in bad health if they are providing substantial care compared with non-carers.

¹⁴ Around **2 million carers** have given up work to care.

¹⁵ Every day around **6,000 people** become carers.

¹⁶ Caring has an impact on health and wellbeing, ability to work, family and other relationships and finances.

⁸ Census 2011, in Facts About Carers 2015, Carers UK

⁹ Valuing carers – the rising value of carers' support, Professor Sue Yeandle and Dr Lisa Buckner, University of Sheffield and University of Leeds, published by Carers UK, 2015

¹⁰ 4.3 million carers up to age 65, 3 million up to age 65 in paid work in the UK according to Census 2011. Analysis by Carers UK, 2014 and 2017.

¹¹ Cowie MR, Wood DA, Coats AJ et al.(1999) Incidence and aetiology of heart failure; a population-based study. European Heart Journal 20: 421–8)

¹² The impact of heart failure is set to rise dramatically over the next 25 years and the proportion will rise by 50% due to a rising elderly population. (Reducing

¹³ the cost of heart failure while improving quality of life June 2013Br J Cardiol 2013;20:45–6 – Authors Richard Brown and Andrew L Clark)

¹⁴ Census 2011, published by Carers UK in Facts About Carers 2015

¹⁵ Carers UK/YouGov poll, 2014

¹⁶ Carers UK, based on work from M A Hirst, published in Carers UK's State of Caring series from 2014, 2015, 2016, 2017

United Kingdom Recommendations

1. The NHS needs to have robust mechanisms in place to ensure that all carers are identified and specifically those caring for people with heart failure. The Government needs to ensure that identification of carers is systematic and matter of course. It needs the NHS Mandate for 2018/19 and subsequent years to set out specific performance measures for this. Government also needs to bring in a duty on NHS organisations to identify carers and to promote their health and well-being.
2. On diagnosis, NHS Trusts need to have mechanisms in place to ensure that carers receive the right package of support that enables them to learn about the condition, how to support the person they care caring for. They also need their own information about rights, entitlements, finances,
3. Local GP practices need to have clear records and mechanisms for having regular checks with carers of people with heart failure. They need to reinforce the information, support and advice package following diagnosis. This is to ensure that needs which develop over time are dealt with.
4. Carers need to be clearly signposted to communities of support whether it be through Pumping Marvellous Foundation, Carers UK and/or local carers support services.
5. Carers need to have the full picture of care and the system so they can disseminate key levers to heart failure patients to help them self-care better and reduce unplanned admissions to hospitals. Joint decision making is important.
6. Employers need to have supportive policies in place for people who are caring for a range of conditions and this includes heart failure.

7. Carers need to be able to access learning materials that enable them to understand the condition, learn about the medication, side effects, etc. to be in a position to support someone with heart failure. They also need tools and learning to be able to manage their own health and well-being and their own lives. This needs to be a core part of delivery of the NHS working in partnership with charities to deliver this outcome.
8. Families, including carers need to be able to access appropriate technology to help the manage conditions and manage care. The evidence is that awareness of how tech can help is low. This needs to be utilised from self-monitoring equipment, to accessing online health records, to apps like Jointly by Carers UK which help people share and coordinate the care.

We know that the prognosis and the effect of the prognosis on the health system for individual patients can be improved through both robust clinical management through an MDT (Multi-Disciplinary-Team) of heart failure specialists however as heart failure lives in the community the carer will play a significant role in helping the patient self-care, they are a definite partner to the broader MDT. Whether that be through drug concordance or the many other challenges that the condition presents like debilitating fatigue, breathlessness and the impact these symptoms bring to bear on the patients ability to live their life. (National Heart Failure Audit April 2015 – March 2016 published August 2017 section 2.4 Discharge and follow up) & (1.5.3 Multidisciplinary team approach to heart failure management & NICE Chronic Heart Failure Guidelines CG108 - 1.5.3.1 Heart failure care should be delivered by a multidisciplinary team with an integrated approach across the healthcare community. [2003]

United States



Heart Failure Carers, United States (IACO Study Sample)

Age (mean)	55.1
Gender (%)	
Men	18 (15%)
Women	103(84%)
Prefer nor to answer	1 (1%)
Ethnic/Racial group (%)	
Non-Hispanic White	98 (82%)
Hispanic	4 (3%)
Black/African American	15 (12%)
American Indian or Alaska Native	0 (0%)
Asian	0 (0%)
Native Hawaiian/Pacific islander	1 (1%)
Other	2 (2%)

¹⁷ Total Population of United States (2017):
323.1 million

¹⁸ Total Number of Carers in the United States:
43.5 million

¹⁹ Annual Economic Value of Their Care: **Over \$470 billion (US)**

²⁰ Percent of Employed Carers in the US: **60%**

²¹ Number of Adults in the US with Heart Failure: Approximately **5.7 million**

²² US Deaths Indicating Heart Failure as a Contributing Cause: **One in Nine in 2009**

²³ Percent of People in the US with Heart Failure Who Die Within 5 Years of Diagnosis: **50%**

²⁴ Estimated Cost to the US from Heart Failure: **\$30.7 billion (US)** Annually. Includes the cost of health care services, medications to treat heart failure, and missed days of work.

¹⁷ US Census Bureau (2017). *US and World Population Clock*. <https://www.census.gov/popclock>.

¹⁸ National Alliance for Caregiving and AARP Public Policy Institute (2015). *Caregiving in the U.S. – 2015*. Bethesda, MD: National Alliance for Caregiving and AARP Public Policy Institute.

¹⁹ Reinhard, S., Feinberg, L.F., Choula, R. and A. Houser (2015). *Valuing the Invaluable 2015 Update: Undeniable Progress, but Big Gaps Remain*. Washington, DC: AARP Public Policy Institute.

²⁰ National Alliance for Caregiving and AARP Public Policy Institute (2015). *Caregiving in the U.S. – 2015*. Bethesda, MD: National Alliance for Caregiving and AARP Public Policy Institute.

²¹ Mozzafarian, D., Benjamin, E.J., Go, A.S., et al. on behalf of the American Heart Association Statistics Committee and the Stroke Statistics Subcommittee (2016). *Heart Disease and Stroke Statistics – 2016 Update: A Report from the American Heart Association*. *Circulation*. 2016; 133: e38-e360.

²² Kochanek, K.D., Xu, J.Q., Minino, A.M., and H.C. Kung. *Deaths: Final Data for 2009 [PDF-3.M]*. *National Vital Statistics Report*. 2011; 60(3).

²³ *Ibid*.

²⁴ Heidenreich, P.A., Trogon, J.G., Khavjou, O.A., Butler, J., Dracup, K., Ezekowitz, M.D. et al. (2011). *Forecasting the Future of Cardiovascular Disease in the United States: A Policy Statement from the American Heart Association*. *Circulation*. 2011; 123(8): 933-44.

U.S. Recommendations

Removing barriers to cardiac rehabilitation:

- Pass Senate Bill 488 to allow physician assistants, nurse practitioners, and clinical nurse specialists to supervise patients in cardiac and pulmonary rehabilitation programs.
- Work with Medicare Advantage programs and private payers to make access and coverage available and affordable.
- Educate physicians and other health care providers about the value of cardiac rehabilitation (CR) in improving outcomes and lowering costs.
- Create incentives for providers and insurers to increase completion rates for cardiac rehabilitation.
- Conduct research into alternatives to traditional CR programs to address logistical barriers.

Improving medication adherence and care management:

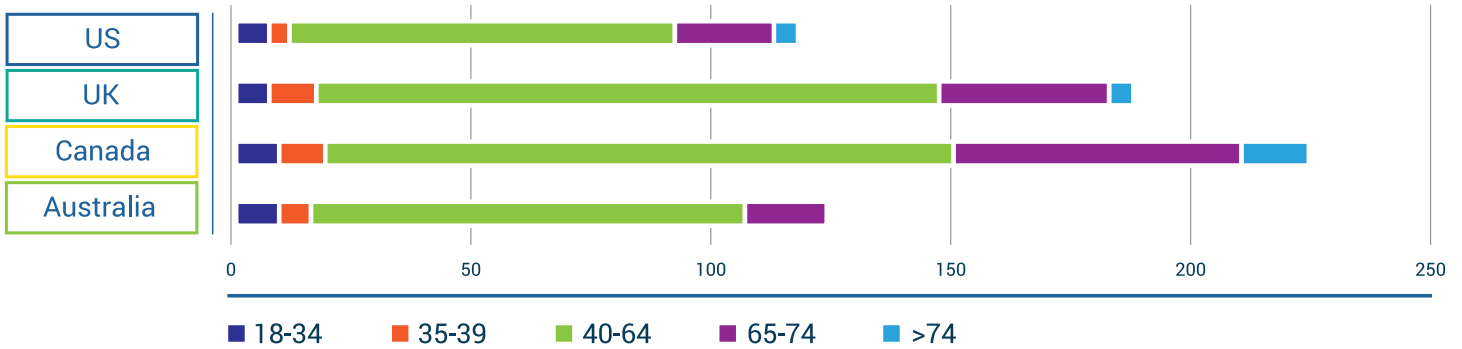
- Incentive pharmaceutical companies to develop “super pills” that reduce the daily pill intake.
- Fund research evaluating the efficacy of home-monitoring programs.
- Implement federal and state policies encouraging patient-centered care teams that include pharmacists, nurse practitioners, facilitators/navigators, and dietitians.
- Provide and pay for education for family and caregivers at discharge and beyond.
- Initiate continuing medical education/continuing nursing education (CME/CNE) certification modeled on diabetes care certification.

Enhancing patient-provider communication:

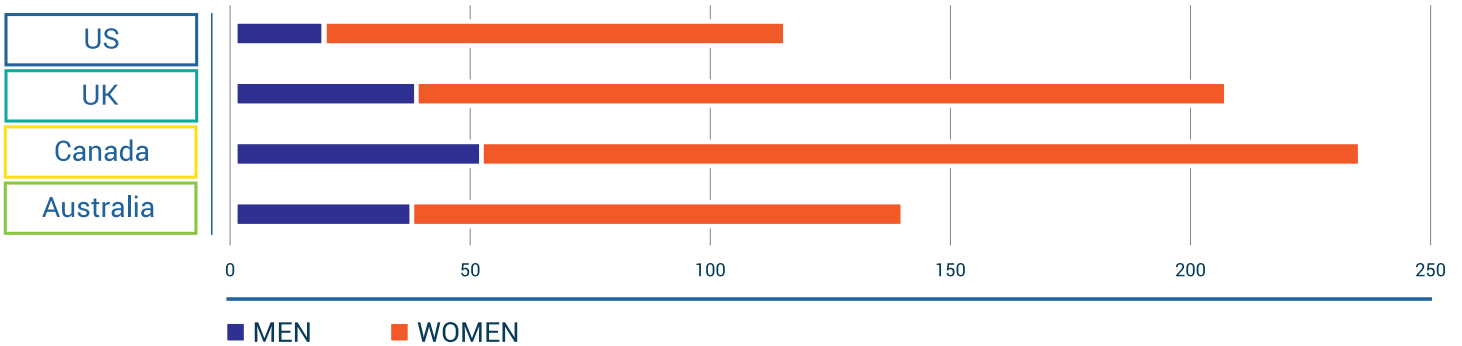
- Modify provider continuing education and recertification curricula to include sex and age sensitivity as well as cultural competency, listening skills, and a holistic approach.
- Educate first-responders on heart failure, particularly in women.
- Improve medical school and residency training on communication skills for better outcomes.
- Incentivize payers to be more proactive on follow up care regarding cardiac rehabilitation.
- Explore telemedicine technology for improved follow-up care.
- Educate carers and encourage patients to track medications, symptoms, and interventions.

Appendix C: Demographic Comparisons of the 4 Nations

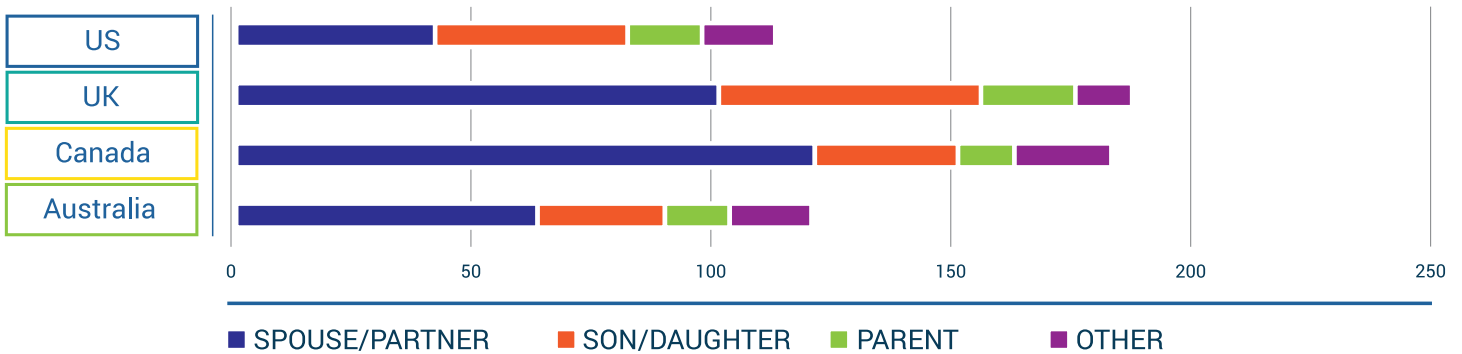
Carers age categories per country



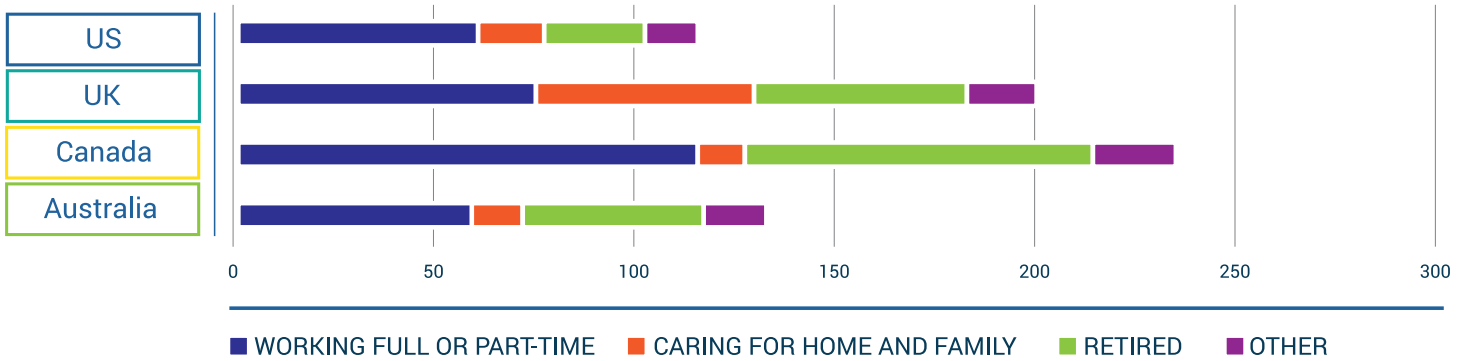
Gender distribution per country



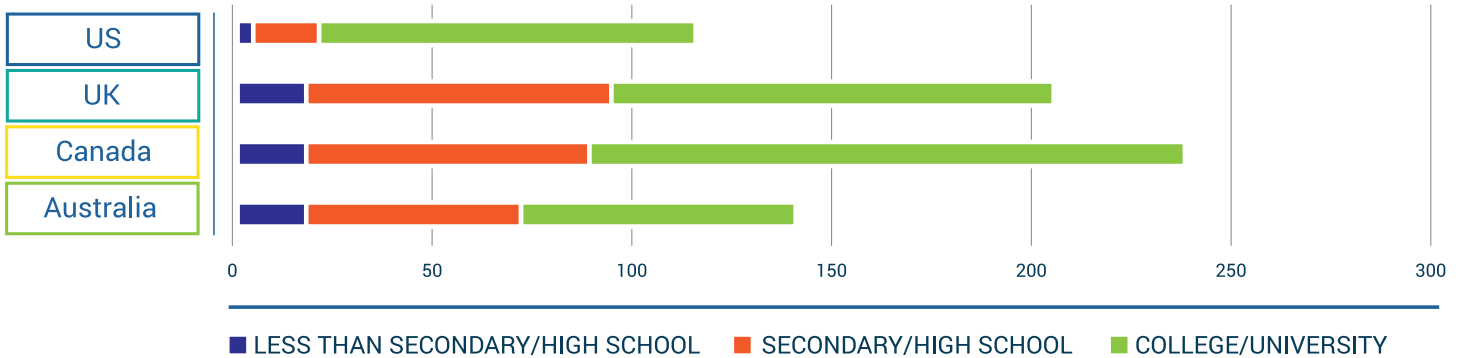
Relationship to patient per country



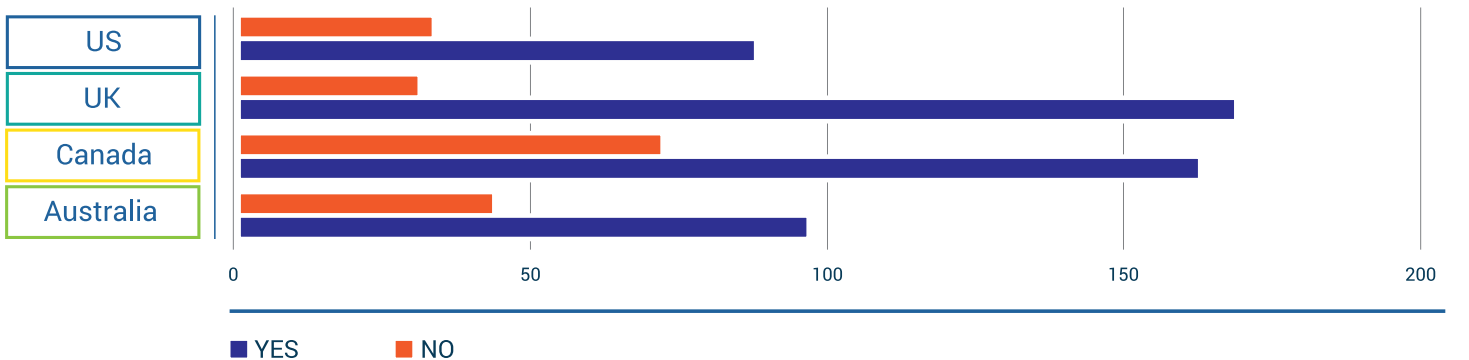
Employment status per country



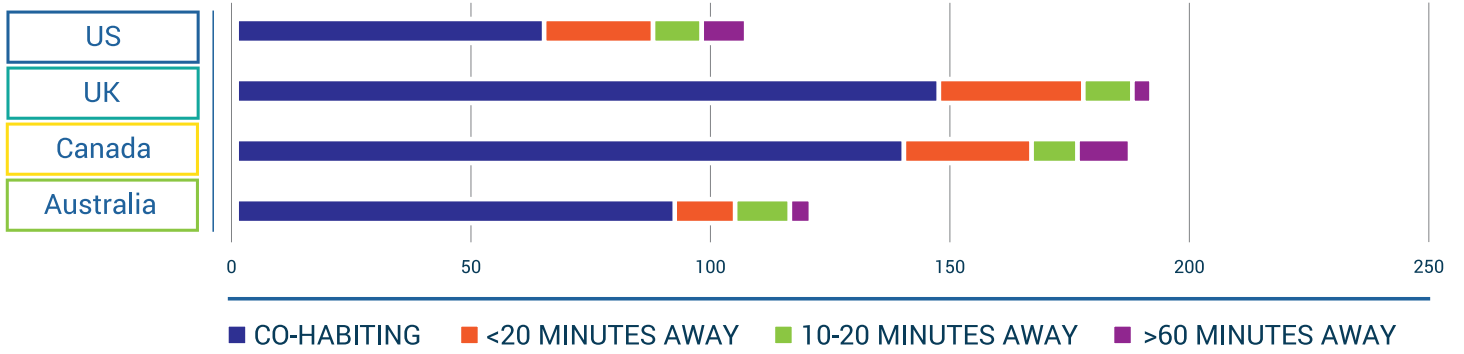
Level of education per country



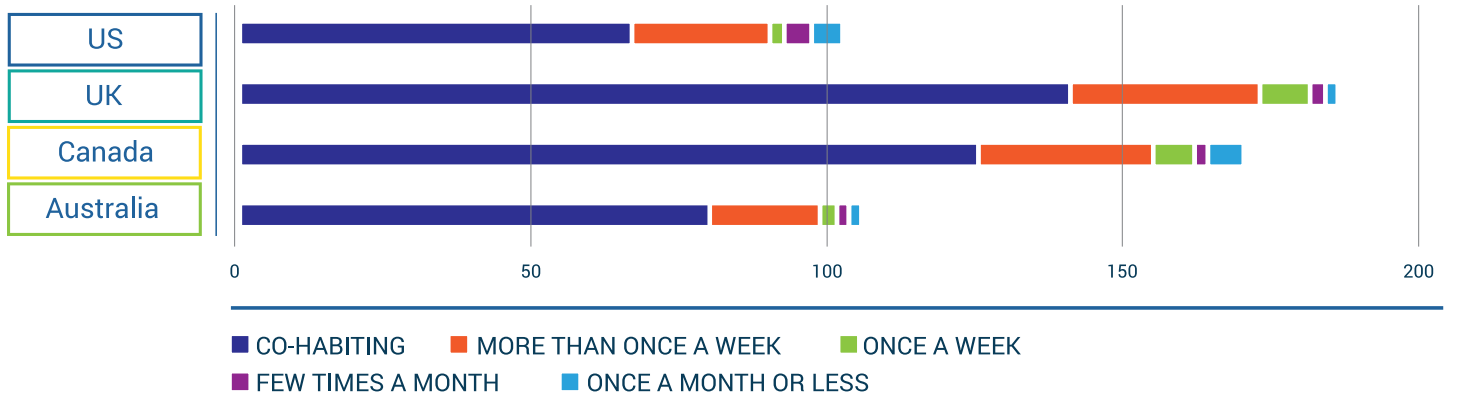
Being the primary carer (N=714)



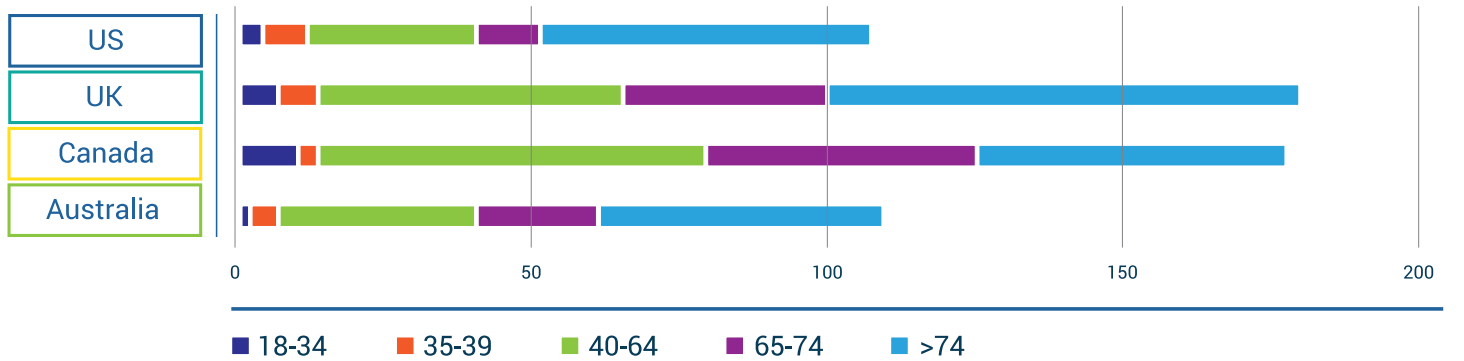
Living arrangements (N=714)



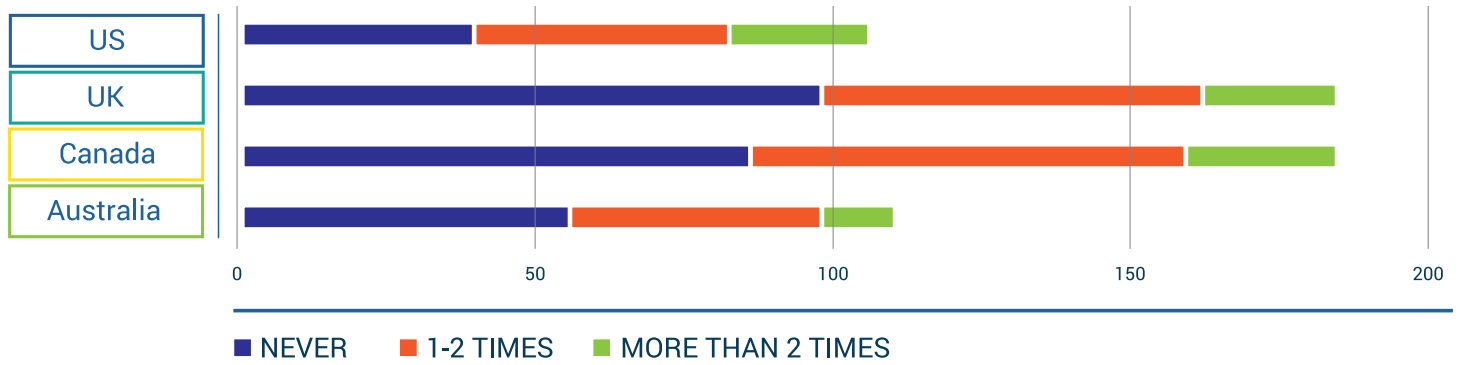
Visiting frequency (N=714)



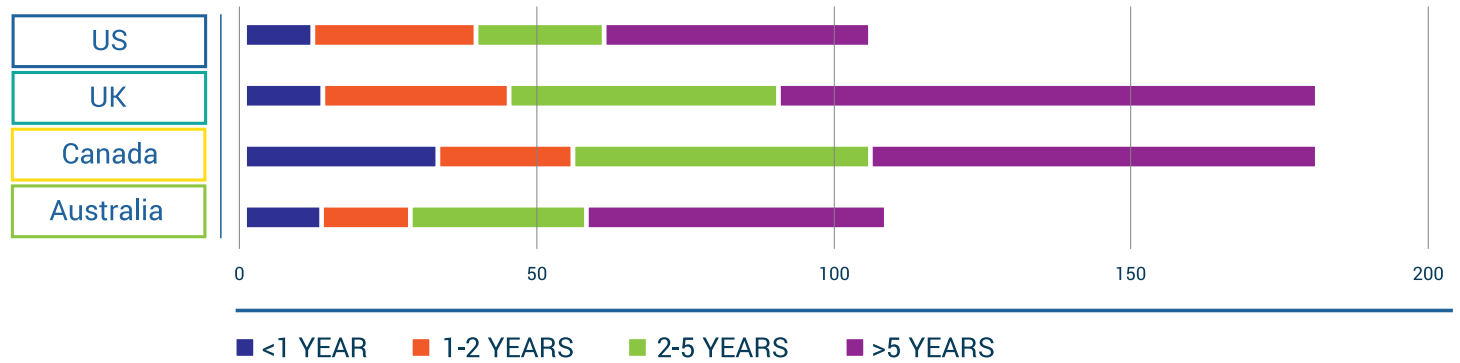
Patients age categories per country



Hospitalised due to heart failure in the last year per country




Time since heart failure diagnosis





International Alliance
of Carer Organizations

Building a global understanding and respect for the vital role of carers



THE INTERNATIONAL ALLIANCE OF CARER ORGANIZATIONS (IACO) IS A GLOBAL COALITION OF 15 MEMBER NATIONS COMMITTED TO BUILDING A GLOBAL UNDERSTANDING AND RESPECT FOR THE VITAL ROLE OF FAMILY CARERS. EACH MEMBER COUNTRY IS REPRESENTED BY A NATIONALLY-RENOWNED CARER ORGANIZATION. THE COALITION MEETS ANNUALLY TO SHARE BEST PRACTICES, IDENTIFY GLOBAL ISSUES, AND ADVOCATE FOR FAMILY CARERS WITH GLOBAL BODIES SUCH AS THE UNITED NATIONS.