A cross-European study of informal carers' needs in the context of caring for older people, and their experiences with professionals working in integrated care settings.

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2 and their experiences with professionals working in integrated care settings.
3
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24

25 **Abstract**
26 *Introduction:* Informal carers are increasingly relied on for support by older people and the
27 health and social care systems that serve them. It is therefore important that health and
28 social care professionals are knowledgeable about and responsive to informal carers' needs.
29 This study explores informal carers' own needs within the context of caregiving; and
30 examines, from the informal carers' perspective, the extent to which professionals assess,
31 understand and are responsive to informal carers' needs.
32 *Methods:* We interviewed (2016-2018) 47 informal carers of older people being served by 12
33 integrated care initiatives across seven countries in Europe. The interviews were
34 thematically coded inductively and analysed.
35 *Results:* Informal carers reported that professionals treated them with respect and made
36 efforts to assess and respond to their needs. However, even though professionals
37 encouraged informal carers to look after themselves, informal carers' needs (e.g., for
38 respite, healthcare) were insufficiently addressed, and informal carers tended to prioritize
39 older people's needs over their own.
40 *Discussion and conclusion:* Informal carers need better support in caring for their own
41 health. Health professionals should have regular contact with informal carers and proactively
42 engage them in ongoing needs assessment, setting action plans for addressing their needs,
43 and identifying/accessing appropriate support services. This will be important if informal
44 carers are to continue their caregiving role without adverse effects to themselves.
45
46

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51 **people, and their experiences with professionals working in integrated care settings.**
52

53 **(1) Introduction**
54 Many older people who live at home receive care (e.g., support with activities of daily living)
55 from informal carers, who include relatives, neighbours and friends [1-3]. While informal
56 carers have reported some positive effects of caregiving (e.g., satisfaction of caring for a
57 loved one) [3,4], caregiving is also known to exert some negative effects on informal carers'
58 health and wellbeing (e.g., exposure to stress) [3,5,6]. Given the key role that informal carers
59 play in the delivery of care to older people, thereby supporting them to live at home longer
60 and avoid costly institutional care, there is a need for health and social care professionals
61 (henceforth professionals) to work more closely with informal carers to identify and support
62 them in meeting their health and social care needs [1,3]. The current study explores informal
63 carers' own needs within the context of caregiving, and their experiences with professionals
64 working within integrated health and social care systems in Europe. The findings will help
65 identify strengths and deficits in the ways in which health and social care systems 'care for
66 informal carers', and in so doing generate knowledge that can inform future efforts aimed at
67 better supporting informal carers.
68

69 **(2) Background**
70 It is estimated that around 80% of all care received by people of all ages in the EU is
71 provided by informal carers, of whom two thirds are women [7]; and 7% and 9% of adults
72 ages 35-49 and 50-64 respectively reported that they provide care to an older person on
73 daily basis [8]. Informal care has been estimated to have an economic value equivalent to
74 50-90% of the overall cost of long-term care across the EU [9]. In the context of demographic
75 ageing and the subsequent increase in the number of older people in need of care, informal
76 care is seen as a way of containing the costs associated with formal care delivery in many
77 countries [9].
78

79 Although informal carers report positive experiences from caregiving, including a sense of
80 giving back to someone who has cared for them, and the satisfaction of knowing that their
81 loved one is getting excellent care [4], caregiving may also negatively affect the health and
82 wellbeing of informal carers. Many informal carers are themselves older in age (e.g., spouses
83 of older people) and may face a greater risk of experiencing carer burden due to their own
84 health and social care needs [10,11]. Caring for sick or older loved ones often comes with
85 demands that can lead to challenges, for example: poor diet and limited exercise [10];
86 reduced quality of life, stress, anxiety and depression [5,12]; social isolation due to being or
87 feeling unable to leave the home because of caring responsibilities [6]; and reduced income
88 [5,13]. Approximately 5% and 8% of midlife women who provide care in the Scandinavian
89 countries and Western Europe reduce their paid work hours or leave the labour force due to
90 caring responsibilities [14].
91

92 Informal carers have varied needs that can change over time [11,15]. Health and social care
93 professionals can play an important role in assessing carers' needs, and in referring them to

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94 or providing them with support in undertaking their role. Such support can enable informal
95 carers to take better care of their own health and wellbeing [1], which in turn may facilitate
96 carers' important contributions to the sustainability of long-term care. However, there are
97 barriers to professionals paying closer attention to informal carers' wellbeing, including lack
98 of clear mandates/requirements to do so, and professionals' busy schedules and limited
99 experience or skills in working with informal carers [1,3]. In the United Kingdom (UK), it is
100 estimated that 70% of informal carers come into contact with professionals due to their own
101 health needs, or because of the needs of the person they are caring for. Yet only one in ten
102 informal carers is identified as a carer by professionals [1]. Moreover, many informal carers
103 do not recognise themselves as having a caring role. Rather they identify themselves as a
104 partner in an ongoing, reciprocal relationship [1]. Informal carers do however consider
105 professionals to be a source of information and support when these professionals are known
106 to the informal carers.
107
108 Given 1) a health and social care landscape that is primarily centred around older people
109 compared to their informal carers [3], 2) the crucial role that informal carers play in caring
110 for older people, and 3) informal carers' own health and social care needs that also warrant
111 attention [3,16], the aim of this study is to examine, from the informal carers' perspective,
112 the extent to which professionals assess, understand and are responsive to informal carers'
113 needs. Integrated care is seen as a promising approach to providing care for older people in
114 their home environments in a proactive and coordinated manner, centered around theirs'
115 and their informal carers' needs [17]. Person-centered care is an important component of
116 integrated care [17,18]. Its key elements include: promoting the client's active participation
117 in making decisions about and managing his/her health and social care needs, promoting a
118 cooperative relationship with the client (respect, active listening, good communication),
119 understanding the client's specific needs and concerns (his/her preferences, priorities),
120 addressing the client's varied needs (paying attention to the whole person), providing
121 coordinated care [18,19]. We aim to gain an understanding (based on informal carers' own
122 reports) of how professionals in such settings consider and respond to informal carers' own
123 needs, and the extent to which those efforts are person-centered.
124
125 **(3) Methods**
126 (3.1) Study design
127 This study was part of the SUSTAIN (Sustainable Tailored Integrated Care for older people in
128 Europe) project—April 2015 and March 2019. Employing a multiple embedded case study
129 design [20,21], data was collected from thirteen established integrated care initiatives for
130 older people across Europe: Austria, Estonia, Germany, Norway, Spain, the Netherlands and
131 the UK. The SUSTAIN project is described in further detail elsewhere [22], and was funded
132 under Horizon 2020 – the Framework Programme for Research and Innovation (2014-2020)
133 from the European Commission.
134
135 Different types of support services (Appendix-A) , organized at the national/regional levels
136 and by voluntary organizations, were available for informal carers in this study; and the
137 health and social care organizations involved in SUSTAIN mainly provided informal carers
138 with information about- or referred carers to the services. All the countries have universal
139 coverage for primary and tertiary healthcare. Germany and Norway also have universal
140 coverage for long-term care and social services; whereas the other countries have mixed-

141   coverage. In Estonia and Spain in particular, long-term care is largely a family responsibility.
142   All the countries provide informal carers with some financial support. Except for Austria and
143   Spain, all countries support carers with flexible work arrangements. All countries provide
144   informal carers with respite services. Additional supports, some from the voluntary sector,
145   include informational resources and/or training, guidance and counseling, support groups,
146   supportive technologies (Germany, Norway, Netherlands, UK) and carers' needs assessment
147   (UK, Netherlands).
148
149   As part of the SUSTAIN project, we conducted semi-structured interviews with informal
150   carers of older people living at home, and receiving care and support from the integrated
151   care initiatives participating in the project (description in Appendix-B). The different
152   initiatives (SUSTAIN sites) included proactive primary care for older people, home nursing
153   and rehabilitative care (both provided by healthcare professionals), transitional care, and
154   care for people with dementia. The participating initiatives mainly centered their activities
155   around providing and improving services for care recipients (e.g., older people) (Appendix-
156   B). Even so, we wish to focus attention on the experiences of informal carers in these
157   settings.
158
159   Ethical approval was provided by ethical review committees in the seven participating
160   countries, and all respondents signed a consent form before the start of the interviews,
161   indicating that: they agreed to participate in the SUSTAIN project, they understood the
162   nature of their involvement, and they gave permission for interviews to be audio recorded.
163
164   (3.2) Data collection
165   Informal carers were recruited using convenient sampling whereby health and social care
166   professionals invited the informal carers of the older people served by the SUSTAIN sites to
167   participate in the study. With the informal carers' permission, researchers scheduled and
168   conducted interviews with informal carers (48 total: 18 older person and carer dyads, 29
169   carers alone). Interviews were conducted at the informal carer's or the older person's home,
170   or at the SUSTAIN site. The individual, face-to-face interviews lasted approximately 60
171   minutes and were conducted by local researchers in each informal carer's national/local
172   language. The interviews explored topics related to our study aim (see the introduction) and
173   were guided by a semi-structured interview schedule (Appendix-C: main interview
174   questions).
175
176   Additionally, we collected data on informal carers' sociodemographic and health service
177   related characteristics (presented in Appendix-D). All data collection tools developed by
178   SUSTAIN research partners were prepared in English and then translated into the integrated
179   care initiatives' national languages. Regular meetings and teleconferences took place
180   between research partners to standardise the methods of data collection in each country. All
181   interviews were audio-recorded and transcribed in the original interview language. Data
182   about informal carers' own experiences (as opposed to older people's experiences) were
183   translated into English for this study.
184
185   (3.3) Data management and analysis
186   Data were managed in a secure online database accessible to SUSTAIN research partners.
187   Strict guidelines for data entry were developed and shared across research partners. Two

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188 researchers, EAA and LM, analyzed the qualitative data and cross-checked each others'
189 work. First, EAA read the transcribed interviews and then applied an inductive approach to
190 identify main themes and subthemes from the content of the interviews [23] (Appendix-E)
191 aided by NVivo 12 software. Thereafter, EAA linked key elements of person-centered care
192 [18,19] to the identified themes (Appendix-E). LM reviewed and analyzed the coded data,
193 and presented the findings. EAA reviewed the findings.
194

195 **(4) Results**
196 The findings from this study are thematically presented below. The themes identified were:
197 assessing and responding to informal carers' needs, understanding carers' role over time,
198 looking after carers' health and wellbeing, carers' participation in decision-making and goal-
199 setting, and informal carers' perceptions of how they are treated by professionals. We use
200 female pronouns in the direct quotes keep respondents anonymous.
201

202 *(4.1) Assessing and responding to informal carers' needs*
203 Professionals made efforts to work with informal carers in a person-centered way by paying
204 attention to and helping informal carers' address their needs and concerns. For example,
205 some informal carers reported that professionals assessed their needs by asking them
206 specific questions or, in some cases, applying standard assessment instruments. Many
207 informal carers expressed that professionals were attentive to their needs, e.g., inquiring
208 about carers' wellbeing and how they were coping during home visits to the older person.
209

210   Carer: "Yes, they ask that every time they visit. 'How are you?' yes, they pay attention
211   to that" (Carer1_Country1).
212

213 Professionals asked informal carers if they needed support, explained how to conduct
214 specific care procedures, and provided useful and practical information about services or
215 support for the carer and the older person. Some informal carers recalled talking with
216 professionals about specific matters that interested them as carers, such as the need for
217 respite.
218

219   Carer: "…when [older person]…was at the nursing home for rehabilitation […]
220   I…asked [the professionals] whether they could take over the administration of her
221   medication. And they listened to that." […] "[Before] I controlled all her medication
222   and picked it up at the pharmacy and ordered new prescriptions and talked with the
223   GP… And I started to feel that it was a lot of work and also a responsibility. I talked
224   with [older person] and she said it was OK, so I talked with home nursing and they
225   took over" (Carer1_Country2).
226

227 However, not all informal carers reported positive person-centred experiences with
228 professionals. Some carers expressed clearly that professionals were not attentive or
229 responsive to their needs e.g., professionals did not ask how they were coping with the
230 caregiving situation.
231

232 *(4.2) Understanding informal carers' role over time, and the need to balance caregiving and*
233 *life/work demands*

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234 Some informal carers commented that they felt that professionals did not fully understand
235 their situation, initially or over time. They perceived that professionals may have assumed
236 that they would serve as caregivers by default despite their own personal challenges (e.g.,
237 physical constraints, reduced endurance/advanced age).
238
239   Carer: "I don't think that they understand our situation. I am in much poorer health
240   than what they believe. […] I have had two big heart attacks and two big operations.
241   And my back is not in good shape" (Carer2_Country2).
242
243 Additionally, several informal carers complained about their own needs and schedules not
244 being considered when professionals scheduled medical appointments for the older people.
245 Examples of things not considered included informal carers' need for sleep or rest, access to
246 transport to health facilities, and the need to balance older people's medical appointments
247 with carers' job demands/schedules. As such, informal carers felt they were not actively
248 involved in decision-making about their needs, preferences, and roles as caregivers.
249
250   Carer: "Well, doctors give you what they can…, for instance, for the [older person's
251   technical device] they always gave her appointments in the morning, and I asked
252   them if it could be in the afternoon, and they…[agreed]. But when it is an already
253   scheduled visit, they say 'that day, that time…' and you go, …if you say you cannot go
254   maybe they reschedule for two months later, so, best thing is not to say anything"
255   (Carer1_Country3).
256
257 Some informal carers stressed that they had little or no follow-up communication or visits
258 from professionals after the older person had completed rehabilitation or was discharged
259 from hospital. Such situations left informal carers without support in their 'new/changing'
260 caregiving role; and suggests that professionals performed poorly with regard to promoting
261 cooperative relationships with carers. Informal carers also expressed that they had no
262 follow-up from professionals after goals were set for the older person in a care plan agreed
263 upon by the professionals, the older person and the carer. Thus, informal carers were left
264 alone with the responsibility of supporting the older person in meeting those goals.
265
266   Carer: "They [professionals] don't contact us to know how the situation is. And
267   regarding the rehabilitation team that was here for 8 weeks, they have not contacted
268   us afterwards…so it feels maybe a bit like a loss, the fact that they haven't followed
269   up on the work that was done here" (Carer4_Country2).
270
271 Informal carers also feared that if the older person's health worsened such that they could
272 not care for him/her properly, they would have to consider sharing caregiving
273 responsibilities with others, or placing the older person in a care home. This last option was
274 the least desired by both older people and their informal carers.
275
276 *(4.3) Looking after informal carers' health and wellbeing, including opportunities for respite*
277 A common message that informal carers received from professionals was that 'they should
278 look after their own health and wellbeing too', and not just that of the older person, in order
279 to not get overburdened or fall ill. To this end, professionals provided carers with different
280 types of advice, including to: eat and rest properly, go outdoors, exercise, maintain social

281 relationships, and take breaks from caregiving. Informal carers also received psychological
282 support or medication when needed. In these ways, professionals made efforts to be
283 person-centred by helping address carers' varied needs. Even so, most informal carers
284 indicated that their health worsened after they became carers; and they expressed feeling
285 that little could be done to change this trajectory.
286
287 Although informal carers did seek healthcare for their minor or temporary health problems,
288 they generally tended to prioritize the needs of the older person at their own expense,
289 despite the severity of their own health problems as carers. For example, informal carers
290 would avoid getting surgery to address a knee problem because they felt that they could not
291 afford to be temporarily disabled or fall ill because they believed that they should be looking
292 after the older person. Several informal carers thus feared for what would happen when
293 their own health gets worse, feeling that no one could take their place as carers.
294
295   Carer: "In case I have to go to a hospital…, there is no Plan B. We wouldn´t know
296   what to do. […] My husband cannot do anything alone. He needs me very much. And
297   [the professional] said to me that I have to look good after myself. I should not
298   overburden myself. That's what she said insistently to me" (Carer1_Country4).
299
300 Many informal carers were offered respite services at some point, or were encouraged to
301 take a break from caregiving and participate in leisure activities. However, some carers
302 declined these offers because they did not want to leave the older person 'alone' e.g., in a
303 care home.
304 Other informal carers also did not feel comfortable leaving the older person at home with a
305 professional. This latter scenario was especially the case for older women caring for their
306 frail or severely dependent spouses at one site, but it was also reported by men caring for
307 their parents.
308
309 Some informal carers who tried respite services commented that it did not work well for
310 them. For example, because of the time and effort needed to commute to an inconveniently
311 located care home to visit the older person. However, other informal carers welcomed and
312 appreciated the opportunity for respite.
313
314   Carer: "…it took me 2-3 hours [via public transport] to get back and forth. And then I
315   stayed with her [the older person at the care home] for 3 hours. But it was a hassle…"
316   (Carer4_Country2).
317
318   Carer: "I think [going to the day center] is good for her [older person], and for me as
319   well – I have to be honest about that. It enables both of us to do a bit of something
320   else" (Carer3_Country2).
321
322 *(4.4) Informal carers' participation in decision-making and goal-setting*
323 Many informal carers could not remember setting any goals, together with professionals,
324 related to their own health and wellbeing needs. Some carers anticipated that it would not
325 be difficult being involved in such shared decision-making if/when needed. Other carers
326 explained that they had outlined together with professionals a plan for how they would look
327 after themselves (e.g., taking breaks, exercising, leisure activities). However, informal carers'

328 input about goal-setting and decision-making regarding their own wellbeing was limited and
329 vague, overall. Informal carers (and professionals) primarily focused on older people's needs.
330
331   Carer: "To my knowledge, there are no goals [set with the professional] … which
332   should be achieved [by the older person or informal carer]" (Carer2_Country4).
333
334   Carer: "Yes, what kind of goals do I have? Haha, I am. Well…, what kind of goals do
335   you still have at this age?" (Carer2_Country1).
336
337
338 *(4.5) Informal carers' perceptions of how they are treated by health and social care*
339 *professionals*
340 Informal carers tended to first think about how professionals treated the older person,
341 followed by how professionals treated them as recipients of care or support. This order of
342 priority influenced informal carers' feelings about how they were treated by professionals,
343 and most carers were generally pleased with the way they and the older people were
344 treated. They described the treatment as 'excellent' or 'very good', expressing that they
345 were treated with respect and sensitivity, and that they felt listened to.
346
347   Carer: "So, I was very satisfied, [the professional] listened very well. Really, listened
348   very carefully" (Carer1_Country4).
349
350 Some informal carers, however, did not have positive experiences with specific
351 professionals. These carers expressed that professionals should be sensitive and considerate
352 of the fact that informal carers who seek their support are often vulnerable, in need, worried
353 for their relatives, and (sometimes) stressed by caregiving demands. One informal carer
354 described how she felt after a negative encounter thus:
355
356   Carer: "You feel like…answering rudely, but you…have to shut up because you think
357   'maybe if you say something they won't give you anything...' [services for the older
358   person]" (Carer2_Country3).
359
360 Specifically, with regard to communication/sharing information, informal carers were
361 satisfied overall with the way professionals communicated with them. In particular, nurses
362 and social workers were often regarded as 'good' and communicative professionals who
363 welcomed informal carers' questions and explained things in a clear, detailed and
364 comprehensive way.
365
366   Carer: "When you are talking with [professionals] in person you understand it,
367   otherwise you ask. But when you receive something [e.g., official letter …] from the
368   government … there is jargon. […], you cannot understand it completely. After that, it
369   is very helpful to have a professional [e.g. social worker] that tells you: 'this is
370   normal'" (Carer3_Country3).
371
372 Physicians, on the other hand, were described by carers as less communicative, did not have
373 enough time to accurately explain things, or used too much jargon that made it difficult to

374   understand the information being shared.

375

376   **(5) Discussion**

377   This study focused on informal carers of older people living at home, who were receiving
378   professional care from integrated health and social care settings in Europe. It described
379   informal carers' experiences with caregiving and with health and social care professionals, in
380   relation to their own needs as carers. An important aspect of integrated care is the proactive
381   assessment of health and social care needs of the older people and their informal carers
382   [19,24-27]. Doing so enables professionals to work in a person-centered way by
383   understanding the specific needs and concerns of older people and their informal carers,
384   and thereafter helping them address those needs appropriately. Findings from this study,
385   however, show that there is room for improvement in terms of the person-centredness of
386   the care and support that informal carers received. For instance, informal carers had mixed
387   experiences with how attentive professionals were to their needs. Needs assessments did
388   not always take place or were experienced as not having been performed. Additionally,
389   across the participating countries, professionals did not always involve informal carers in
390   setting goals and plans for addressing carers' own health and social care needs; or in
391   decision-making about carers' preferences and roles. Professionals further seemed to
392   perform poorly with regard to promoting cooperative relationships with informal carers.
393   Moreover, although professionals made efforts to support informal carers by providing them
394   with advice and opportunities for respite, potential barriers to carers' uptake of support and
395   respite (e.g., challenging emotional aspects of caregiving) were hardly discussed.

396

397   The countries represented in this study have different types of support services for informal
398   carers that are provided by both the public and the voluntary sector (Appendix-A); and
399   informal carers reported that professionals provided them with advice and information to
400   support their own health and wellbeing as carers. Even so, the findings suggest that it is
401   informal carers' loved ones (older people) who are primarily prioritized by professionals in
402   terms of needs assessment, goal setting and care planning. This was the case even though
403   research indicates that the assessment of informal carers' needs is also important [3,28];
404   and that informal carers living in areas where needs assessments were available had better
405   access to information, care and support [28]. The UK and the Netherlands, two countries in
406   the current study, are making progress in the right direction. The UK's Care Act of 2014 [29]
407   has a legal requirement for informal carers to have a needs assessment; and in the
408   Netherlands, such assessments are part of the health and social care system although they
409   are yet to be systematically and consistently implemented. Efforts such as these create room
410   for professionals to engage informal carers around the carers' own needs.

411

412   Existing research also shows that the establishment of an accommodating, cooperative and
413   ongoing relationship between the professional, the person receiving care and the informal
414   carer, including respectful communication and active listening, is an important aspect of
415   integrated and person-centered care [30,31]. The informal carers in this study were
416   generally satisfied with the person-centered way in which professionals interacted with
417   them: e.g., treated them with respect, communicated with and listened to them, and took
418   an interest in their roles as informal carers (e.g., inquired about their wellbeing and need for
419   support). Additionally, in general across the participating countries, informal carers reported
420   that professionals provided them with informational resources. This is consistent with

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421 informal carers' national contexts (Appendix-A) where they have support in the form of
422 information (e.g., knowledge, advice, and services also from voluntary organizations). Our
423 results did however point to some areas of improvement, including that professionals
424 should: interact with informal carers with sensitivity and consideration as carers may
425 themselves be vulnerable (e.g., burned out, stressed), communicate with informal carers
426 effectively (e.g., use less jargon), and follow up with carers more closely regarding the care
427 of the older person. Taken together, these findings can provide other professionals with an
428 understanding of what informal carers need and appreciate in their relationships with
429 professionals. They show that professionals should continue to focus attention on person-
430 centered care, especially developing good relationships with informal carers that create
431 room for talking with carers and understanding their specific needs and concerns.
432
433 Another area of improvement towards better quality of care and support for informal carers,
434 based on results from this study, is that professionals should be more attentive to how
435 informal carers are coping with the caregiving situation, and the impact of caregiving in their
436 daily lives. In accordance with findings from other investigators [32], several informal carers
437 in this study indicated that there seems to be insufficient room for balancing caregiving with
438 other aspects of their lives, including looking after their own health needs, and balancing
439 caregiving with their work schedules and demands, family life, and leisure time. Research
440 shows that women are overrepresented in informal caregiving [2,33]. In this study, there
441 were twice as many female as there were male informal carers under age 65. Occupying this
442 role has been shown to have negative consequences for women more so than men
443 including: losses in income, career development, and social engagement linked to exiting or
444 reducing their participation in the labor force [2,3,10]; health problems linked to the
445 foregoing losses [2,3,33]; and health problems associated with exposure to stress emanating
446 from the demands (and gender disparities therein) of juggling multiple social roles e.g.,
447 family, work, informal caregiving [3,16]. It is therefore essential that informal carers, and
448 particularly women, receive good support from their families, especially their
449 partners/spouses (e.g., equitable distribution of household responsibilities, childcare,
450 informal caregiving); and from the state e.g., paid care leave, flexible work arrangements
451 that facilitate balancing work and family life, childcare and opportunities for respite from
452 caregiving—support that can reduce or protect against the negative consequences of
453 informal caregiving.
454
455 In general, informal carers across the countries participating in this study did not report
456 experiencing financial strain associated with their caregiving role. In Estonia and Spain,
457 caring for family members in need of long-term care is largely the responsibility of the
458 family. Therefore, it could be that informal carers from these countries did not expect much
459 support from their health and social care systems, and may have underreported deficits in
460 informal carer support services/resources. The previously mentioned gender considerations
461 in caregiving may also be heightened for female informal carers in Estonia and Spain. Our
462 findings on financial strain may also partly reflect informal carers' national contexts where
463 carers were provided with some financial support (allowance, care support benefit) and/or
464 flexible employment arrangements (Appendix-A). The voluntary sector in many of the
465 countries was also involved in supporting carers. Additionally, respite services (e.g., adult
466 day centers, short-term institutional stay), and guidance/counseling and training were also
467 available for informal carers at the national level across the participating countries. Even so,

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468 some informal carers in the study were reluctant to receive respite from caregiving because
469 they considered themselves primarily responsible for caring for the older person, and were
470 thus unsure about entrusting another person with the responsibility. These findings point to
471 opportunities where professionals could have worked with informal carers in a more person-
472 centered way. For example, through closer relationships with carers characterized by good
473 communication, professionals could have had discussions with carers about the challenging
474 emotional aspects of caregiving; and encouraged carers' participation in identifying and
475 making use of appropriate support services such as counselling.
476
477 Complex emotions are a barrier to informal carers seeking and accessing support, and they
478 include embarrassment, guilt [1], anxieties around handing over care [34], and a desire to
479 keep the caregiving situation private especially if the person with care needs does not want
480 help from outside the home [1]. Caring may be seen as a normal part of the relationship
481 between the informal carer and the care recipient, and there may also be doubts about the
482 benefits of external support or the associated costs [35]. Open, honest and respectful
483 relationships between informal carers and health and social care professionals are an
484 important element of person-centered care [18,19]; and such relationships are needed to
485 help informal carers overcome barriers to seeking and accessing support [1,3,34].
486 Professionals should further bear in mind that the needs of informal carers may change over
487 time, depending on the situations of the older people they are caring for and also informal
488 carers' own life circumstances [3,11]. Regular assessment of informal carers needs is
489 therefore key to delivering person-centered care characterized by professionals having a
490 good understanding of informal carers' specific needs and concerns, and helping carers
491 address those specific but varied needs that they have (as whole people e.g., needs in the
492 areas of physical and social health, complex emotions of caregiving).
493
494 The informal carers in this study tended to prioritize the health and wellbeing of their loved
495 ones over their own needs, a finding that has also been reported in other recent studies
496 [5,6,10,12,13]. Given the overrepresentation of women in informal caregiving [3,33], this
497 finding may have consequences for gender disparities in the deleterious effects of
498 caregiving. Similarly, this study and others [1,3] also show that professionals mainly focus on
499 the needs of older people (care recipients). That informal carers' health and wellbeing needs
500 are secondary to those of the older person may also explain our finding that both informal
501 carers and professionals did not proactively seek out opportunities to set goals for informal
502 carers' health and wellbeing, and plans for meeting them. It is very important to pay explicit
503 attention to informal carers' needs in order to reduce or prevent caregiver burden, reduce
504 gender disparities in health, and maintain carers' healthy perseverance in the caregiving role
505 over time.
506
507 Informal carers in this study reported that professionals provided them with advice about
508 self-care, and information about services like respite and support groups. Professionals can
509 further help informal carers by engaging them in discussions about their needs and wishes,
510 helping them set plans for meeting those needs, and identifying and guiding them to
511 additional support services such as counselling, therapy, and workshops/training sessions on
512 self-care and coping with the demands of caregiving [36,37]. That said, professionals' busy
513 schedules and limited experience working with informal carers on the carers' own health
514 and social care needs [1,3] are challenges that health and social care systems, and nations at

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515 large, must tackle if they value the contributions of informal carers; and if they are
516 committed to providing carers with person-centered services that prioritizes carers' needs.
517 Findings from this study suggest that professionals made some efforts to work with informal
518 carers in a person-centered way. However, those efforts were limited and mostly centered
519 around treating and communicating well with informal carers, and learning about- and
520 addressing some of their needs (e.g., informational support, advice; opportunities for
521 respite). Other key elements of person-centered care were poorly attended to, such as
522 promoting informal carers' active participation in making decisions about and managing
523 their health and social care needs, addressing carers' varied needs (i.e., paying attention to
524 the whole person), and providing them with coordinated care.
525
526 *(5.1) Methodological considerations*
527 A strength of this study is that it was based on qualitative data from informal carers in seven
528 European countries, yielding findings that can lend perspective on the experiences of
529 informal carers in Europe. The instruments used to gather data from informal carers
530 (questionnaire for sociodemographic data, semi-structured interview guide) were jointly
531 developed by SUSTAIN research partners in the participating countries, allowing for
532 uniformity across the countries. The instruments were then translated into the local
533 languages, and researchers tailored them (defining/explaining terms and concepts during
534 the interviews) to ensure that informal carers understood the questions. We however
535 acknowledge that differences in the professional backgrounds of SUSTAIN researchers across
536 the seven countries, and differences in informal carers' own backgrounds, may have
537 influenced data collection with regard to a uniform understanding of terms, concepts and
538 questions; and in terms of the richness of the data gathered. For example, some informal
539 carers did not understand when asked whether their needs had been assessed and were
540 thus not able to provide a clear answer. Even so, our thematic coding and analysis of the
541 data allowed us to pay attention to- and consider together the similarities and differences
542 emerging from the data and informal carers' input.
543
544 The informal carers in this study come from different countries with different cultural
545 backgrounds and life trajectories. These differences likely affected the way they engaged
546 with the integrated care initiatives at each setting, and the way they responded to the
547 different topics explored in the interviews. Even though SUSTAIN, being a cross-country
548 project, should lend itself well to a cross-cultural analysis of informal carers' experiences,
549 this was not the focus of the project. We thus lack the data needed for such an analysis,
550 which is a limitation of this study. Even so, the findings reported here do shed some needed
551 light on informal carers' experiences with caregiving and with health and social care
552 professionals in Europe.
553
554 The findings of this study are based on informal carers' own reports and perspectives, and
555 lacks input from the older people being cared for and health and social care professionals,
556 which is a limitation. The viewpoints of all three (older people, informal carers,
557 professionals) would have contributed to a richer understanding of how the complex
558 interactions between them, and the systems in which they operate (e.g., health and social
559 care, family, work), influences how informal carers care for themselves and are cared for.
560
561 **(6) Conclusion**

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562 The demographics of aging populations are such that an increasing number of older people
563 are living at home with chronic health conditions requiring health and social care services. At
564 the same time, the health and social care systems that serve older people cannot be
565 depended upon as the only source of long-term care given budget constraints. Informal
566 carers make substantial contributions to caregiving, however, there is a need to pay
567 attention to- and support them in caring for their own health and wellbeing. This is
568 important if informal carers are to continue in their role without adverse effects to
569 themselves (e.g., burnout, ill-health, social isolation).
570
571 Findings from this study indicated that, in general, health and social care professionals
572 listened to informal carers, treated them with respect, and made efforts to assess and
573 respond to their needs. Even so, the results suggest the need for professionals to interact
574 with vulnerable informal carers with sensitivity and consideration, communicate with
575 informal carers effectively, and follow up with them more closely regarding the care of the
576 older person. A better understanding is also needed of informal carers' caregiving situation
577 and how they are coping. The findings also suggest the need to proactively involve informal
578 carers in shared decision-making aimed at identifying goals for informal carers' health and
579 wellbeing, and setting plans to achieve those goals. Additionally, informal carers need to be
580 further supported in gaining a better balance between their caregiving role and their other
581 roles, interests, and health and wellbeing needs. This includes guiding them to services that
582 can help them address their needs, such as difficulty entrusting others with the care of the
583 older person when needed.
584

585 **(7) Declarations**
586 *(7.1) Funding*

592

593 *(7.2) Conflict of interest*
594 The authors have no conflict of interest.
595

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Appendix-A. Support for informal carers within the health and social care contexts of the countries participating in the SUSTAIN project							
Source: Information compiled by SUSTAIN researchers							
Type of support	Support available at: National/local level (X), SUSTAIN site (S)						
	Participating countries[a]						
	AT[a]	DE[a]	ES[a]	NL[a]	NO[a]	SP[a]	UK[a]
Healthcare (primary and tertiary)							
1 Universal coverage (public/taxed-based funding, private insurance, mixed public and private; out-of-pocket/co-payment for some services)	X	X	X	X	X	X	X
Long-term care and social services							
2 Universal coverage (public/taxed-based funding, private insurance, mixed public and private; out-of-pocket/co-payment for some services)		X			X		
3 Mixed (universal and means-tested coverage)	X[h]		X[g]	X		X[b,g]	X
Financial, employment, care-leave related support							
4 Financial support (allowance); Care support benefit, paid care leave	X	X	X[b]	X[b*]	X[c]	X[c](S[h])	X (S[h])
5 Employment accommodations (e.g., flexible work arrangements)		X	X	X	X		X
Support from the health and social care system							
6 Respite services and supports (e.g., provision of/referral to adult day centers, short-term institutional stay; GPS and other welfare technology)	X	X	X[b,d]	X[b,d]	X	X[d*]	X[d*]
7 Engaging voluntary sector/volunteers to support informal carers (e.g., in their role as caregivers, providing them with opportunities for respite)	S	X(S)	X[e]	X[e]	X	S[e]	X(S)
8 Information (e.g., available support services including from voluntary organizations/centers; relevant laws, carers' rights, courses)	X	X	X[b]	X	X	X	X
9 Training, guidance/counseling	X	X	X[e]	X	X	X	X
10 Supportive technology		X[e]		X	X		X
11 Informal carer's needs assessment				X[e](S)		S[e]	X(S)
Support from organizations, foundations, centers							
12 Voluntary sector engagement/support of informal carers (e.g., in their role as caregivers, practical support, opportunities for respite, advocacy for carers)	S	X[b]	X	X[b*]	X		X
13 Information (knowledge, guidance, advice; available support services; sharing of experiences with caregiving)	X	X[b]	X[e]	X	X	X[f]	X
14 Training, counseling, emotional support; guidance, advice, mentoring	X	X[b]	X[d]	X	X	X[f]	X
15 Support groups		X[b]		X	X[b]	X[f]	X[f*]
16 Supportive technology				X			X

Notes: [a]AT (Austria), DE (Germany), EE (Estonia), NL (Netherlands), NO (Norway), SP (Spain), UK (United Kingdom); [b]Service is (also*) organized at the local/regional level, hence there may be variation across localities; [c]Service is selective i.e., for informal carers who meet certain criteria e.g., caregiving hours, heavy caregiving workload; [d]Service is (may also be*) means-tested; [e]Limited or variable/unsystematic availability; [f]Service (also*) provided by organizations concerned with specific diseases e.g., Alzheimers Society; [g]Caregiving/long-term care is largely considered the responsibility of the family, hence heavy dependence on informal carers; ; [h]Professionals provided carers with information about available benefits; [h]People who are not insured are not covered.

Appendix-B. Health and social care sites participating in the SUSTAIN project		
Country	**Integrated care site (location) & Type of services**	**Description of the care site & SUSTAIN improvement project objective**
Austria	Gerontopsychiatric Centre (Vienna) *Dementia care*	"[A] centre for community-based gerontopsychiatric consultancy (clinical-psychiatry and neurology) and serves as a service centre for patients, their families (carers) and for other stakeholders in health and social care… [The multi-professional team] … address the needs of older people suffering from cognitive decline, related morbidities and social problems." SUSTAIN objective: To improve detection of dementia and case- and discharge management of hospitalised people identified with a cognitive disorder.
Estonia	Alutaguse Care Centre (Ida-Viru) *Home nursing & rehabilitative care*	"The nursing and health care services […] are cultivated based on the real needs of senior citizens… […] The Care Centre has five different service areas: round-the-clock special-care services for adults with special mental needs; 24-hour care (nursing home service); care for persons suffering from dementia; day nursing/care; and nursing treatment (health service)." SUSTAIN objective: To develop a person-centred way of working by engaging older people, informal caregivers and a multidisciplinary care team in the process of defining a goal-directed care plan.

	Medendi (Tallin) *Home nursing*	"Medendi is a small private [home nursing company funded by the National Health Insurance Fund]… Home nursing aims to help service users who are recovering from operations, the elderly, the disabled and [other in need of care]. […] Its services are delivered through a multi-agency partnership with other service providers: … physiotherapists, family doctors and palliative nurses…" SUSTAIN objective: To increase the engagement of the older person, informal caregiver and different professionals in the development of a joint care plan, and to support information exchange between the older person, informal caregivers and professionals about the older person's situation, needs and objectives.
Germany	KV RegioMed Zentrum Templin (Uckermark) *Rehabilitative care*	"The integrated care programme of the KV RegioMed Zentrum in Templin provides a three-week complex therapy programme. During this programme service users (older people) are learning about their medication plan, falls prevention, healthy diet and lifestyles and their social needs. They receive a detailed and tailored care plan." SUSTAIN objective: To enable people with care needs (including people who completed a complex therapy program) to receive the right services, by providing information and advice on available care and support services.
	Careworks Berlin *Home nursing and rehabilitative care*	"The Pflegewerk Berlin (Care-Works Berlin, CWB) serves a varied population in less affluent parts of the city. … In the integrated care initiative of Pflegewerk Berlin: nurses, medicines and therapists are involved. Furthermore, the Pflegewerk [serves people] ranging from self-funded service users to those covered under social long-term care insurance and those who need support from the social services department." SUSTAIN objective: To improve inter-professional case management and multidisciplinary collaboration between general practitioners, (para)medical therapists and nurses by transferring prescription-competence from General Practitioners to (para)medical therapists and nurses; and to establish formalised interactions and communication space among involved (formal and informal) caregivers.
Norway	Holistic Patient Care at Home (Surnadal) *Home nursing and rehabilitative care*	"Surnadal's healthcare services are available for all residents. They include but are not limited to general practitioner (GP) services, emergency care, long-term institutional services, physiotherapy and occupational therapy, mental health and homecare services." SUSTAIN objective: To expand and improve healthcare services delivered at home.
	Everyday Mastery Team (Søndre Nordstrand, Oslo) *Rehabilitative care*	"Søndre Nordstrand is the largest and youngest borough in Oslo municipality. […] Everyday Mastery Training (EMT) service …provides rehabilitative care (including training in ADLs) to users in their homes for 4-8 weeks. The health and social care services provided in Søndre Nordstrand […] include emergency care, GP services, nursing homes, Day Center, senior center, homecare services, mental health services, and rehabilitation including EMT. The services are available for all residents of the borough.2 SUSTAIN objective: To increase people's sense of personal control, reduce reliance on traditional care services and maintain and encourage good functional ability and social participation among older people.
Spain (Catalonia)	Severe Chronic Patients/ Advanced chronic disease/ Geriatrics (Osona) *Proactive primary and intermediate care*	"The Osona Program […in collaboration with partners] serve a population of approximately 155.000 inhabitants, of which 2.58% are users with complex health and social needs. This unique configuration brings together local public sector entities involved in the care continuum of 65+ users with chronic health conditions and complex social and health needs: primary health care nurses and GPs delivering home and ambulatory care; social workers assessing home environments and social-relational networks; specialist doctors for several chronic conditions, and acute and intermediate hospital staff caring for these users both as outpatients and inpatients." SUSTAIN objective: To improve person-centeredness of care by conducting a standard, multidimensional joint assessment and elaborating a shared individualised care plan among involved health care and social care professionals and the older people and informal caregivers.
	Social and health care integration (Sabadell) *Proactive primary care*	"Services [in the program] …include three Primary Health Care Centres (PHCC) in north Sabadell […]and the local social services provided by Sabadell's city council. Thirteen professionals form the small team, including: two managers (1 health and 1 social sector) and a triad of GP, nurse and social worker for each PHCC. […] The North Sabadell Social and Health Care Integration Program was launched for 65+ users with complex health and social needs. When a user met criterion for this program, they were signed-up into a shared agenda, so their case could be discussed and assessed by the triad in their monthly coordination meeting." SUSTAIN objective: To establish a systematic, multidimensional assessment and care plan tailored to multiple health and social care needs of each older person and to establish care plans that people feel knowledgeable and active about, targeted at those unknown to social services.

The Netherlands	Geriatric Care Model (West-Friesland) *Proactive primary care*	"Over the last years, [West-Friesland] has been the context for various activities targeting care and support for older people living at home with complex care needs, [… including implementation of] the Geriatric Care Model (GCM) [in one region] Municipalities in the Netherlands are legally responsible for delivering social care and support services, as well as for providing instrumental needs to help people living at home for as long as possible. They collaborate with home care organisations and social care organisations in local social community teams in order to fulfil this responsibility. Other activities in the region include comprehensive case management for people with dementia and their caregivers… Following the implementation of the GCM in West-Friesland, the regional GP organisation agreed for the West-Friesland region to be included as one of the Dutch case sites of the SUSTAIN project." SUSTAIN objective: To improve collaboration between General Practitioners and practice nurses, case managers for people with dementia and the social community team in order for them to adequately address older people's health and social care needs; and to improve professionals' person-centred way of working.
	Good in one Go (Arnheim) *Transitional care*	"In the Eastern part of the Netherlands, the Arnhem region…several organisations work together to deliver person-centered health and social care services for older people. 'Good in one Go'… specifically focused on crisis situations of frail older people living at home. In the project, organisations collaborated in an informal network, which means that organisations did not have any formal agreements, but aligned their activities in order to provide a comprehensive range of health and social care services in the region." *SUSTAIN objective:* To clarify and align the various scenarios of a sudden need for more intensive care of a person living at home in a crisis (such as dementia or brain injury).
United Kingdom	Over 75 Service (Kent) *Proactive primary care*	"Swale is the third most deprived district within Kent… In Kent, the county council is responsible for social care services and provides formal care services in residential care homes and in people's own homes. Kent County Council (KCC) manages the Kent Enablement at Home (KEaH) service …which provides up to 3 weeks' support at home for people returning from hospital. KEaH staff work with users to learn or relearn important skills they need for everyday life, such as regaining confidence following a fall. KCC also employ care navigators who help older people to stay independent in their own home. […]Swale is also served by Swale Borough Council, [which is] responsible for housing and planning, amongst other things, and provides help and advice for older people dealing with repairs, adaptations and home safety issues to help them to stay in their own home…" *SUSTAIN objective:* To keep older people with long-term conditions and complex care needs at home independently for as long as possible and to improve care coordination across existing services around these people.
	Swale Home First (Kent) *Transitional care*	"Sandgate Road Surgery is a General Practitioner (GP) Medical Centre in Folkestone in the South East of England. […] The target group for the Over 75 Service were: people aged 75 and over; frail, housebound and vulnerable; living alone or with a spouse with limited social or family support; complex health and social care needs and at high risk of hospital (re) admission. […]The Over 75 Service has a core team based at the surgery consisting of a Lead GP, Senior Nurses called 'Practice Matrons', a paramedic practitioner and administrative staff. There is a wider multidisciplinary team from health, social and voluntary sector organisations… As a result of this extensive team, a range of services are delivered including medical and nursing care, social care, health training, independence co-ordination, care navigation, carer support and medicines management." *SUSTAIN objective:* To ensure medically optimised hospitalised people are able to be discharged straight home with the right support and to make the person's discharge smoother, quicker and safer by moving to a single assessment.

Source: Adapted from De Bruin et al., 2018 [7,35]; and SUSTAIN country reports (Austria, p. 11; Spain, p. 12, 29; Estonia p. 10, 24; UK p. 10, 25; Germany p. 10, 25; Netherlands p. 11, 26; Norway p. p. 10, 25): https://www.sustain-eu.org/products/sustain-country-reports/

Appendix-C. Caregiver interview questions

1. How do the workers (e.g. nurses, social workers, occupational therapists, health assistants) who provide care to [older person] treat you?
    a. How do you feel about the way you are listened to and respected for what you say?
2. Do you know who [professional] to contact…if you need to ask questions about [the older person's] conditions and care?
    a. How well do you feel this person [professional] understands your…needs?
3. Do you feel the workers are meeting your own needs?
    a. Do you feel that all your own needs are assessed properly?
    b. How have your needs been assessed, and how did you experience this (e.g. did you feel safe/secure to share all the needs you have)?
4. Do you have the opportunity to discuss your needs with the health workers, and are you involved in making decisions about how your own needs (e.g., for respite) can be met?
5. Please describe any goals related to your health and wellbeing that have been set for you. How involved were you in developing

the goals?
- a. Have you achieved your goals?
- b. Has a professional evaluated the extent to which you have achieved your goals?
6. To what extent are you, yourself, offered any support in dealing with any emotional effects of caring for [the older person] (e.g. support groups, respite from caring)?
7. Do you feel supported to do most of the things you want to do outside your care work? (e.g. work, socialising, physical activities, leisure, study)?

Appendix-D. Characteristics of informal carers of older people living at home (N = 44)		
Characteristic	N	Percent/ Mean(SD)
Country		
Catalonia (Spain)	5	11.4
Germany	5	11.4
Norway	8	18.2
Netherlands	12	27.3
United Kingdom	9	20.4
Austria	2	4.6
Estonia	3	6.8
Female (/male)	14	68.2
Age		
25-34 years	1	2.3
35-44	1	2.3
45-54	5	11.4
55-64	9	20.5
65-74	7	15.9
75-84	19	43.2
85+ years	2	4.5
Education		
Primary	11	25.0
Secondary	17	38.6
Further education	12	27.3
Higher education	3	6.8
Missing	1	2.3
Marital status		
Married/cohabiting	40	90.9
Separated/divorced	2	4.5
Single	2	4.5
Relationship to older person		
Spouse/partner	30	68.2
Son	5	11.4
Daughter	6	13.6
Other family/relative	2	4.5
Other	1	2.3
Living situation (proximity to older person)		
Living with the older person	29	65.5
Living close by (<5 km)	12	27.3
Living further away (>5 km)	3	6.8
Paid job		
Yes	14	31.8
No	29	65.9
Missing	1	2.3
Paid working hours per week (where reported)	13	29.4 (11.5)
Caregiving hours per week for carer not living with older person (where reported)	13	17.0 (14.2)
Caregiving hours per week for all carers (where reported)	23	33.7 (41.6)
Carer's needs assessed by a healthcare professional		
Yes	9	20.5
No	28	63.6
Missing/don't know	7	15.9
Carer has a care plan		
Yes	4	9.1
No	28	63.6

Missing/don't know	12	27.3

Description: Table 1 shows the characteristics of 44 of the 47 informal carers in this study for whom quantitative data was available. Over two-thirds of the informal carers were female, many (63%) were age 65+, and under one-third had attained a post-secondary education. All but one informal carer were kin. Most informal carers were the spouse/partner of the older person; and sons and daughters were nearly equally represented as carers. The majority of informal carers lived with the older person. The few informal carers who had a paid job worked an average of 29 hours per week. Most informal carers who lived with an older person did not report hours spent on caregiving activities given the difficulty of disentangling them from daily household chores. Informal carers who did not live with an older person reported an average of 17 hours per week spent on caregiving (range 2-48). A minority of informal carers (20%) reported that their own needs had been assessed (16% did not know). Additionally, only one in ten informal carers report that they had their own care plan (27.3% did not know/provide the information).

Commentary: That the informal carers are somewhat homogenous (i.e., approx. 68% female, 68% spouses/partners, 63% aged 65+) suggests that women [37,40] and spouses/partners who are themselves older [37] are especially represented in informal/family care of older people. That few informal carers had higher education (6.8%) might be because many informal carers in the study are of an older generation (born in the early 1950s), a cohort who—unlike children of later decades—were less likely to attain a higher education [41].

Appendix-E. Analysis themes and subthemes
(Addressing informal carers' own health and social care needs: carers' reports of their experiences with health and social care professionals)

Themes	Subthemes	Relevant elements of person-centered care (also see part 2 below)
1. Assessing and responding to informal carers' needs	a. Needs assessment b. Paying attention to/inquiring about carers' wellbeing, need for support c. Talking with carers about matters that interests them d. Providing carers with information and guidance	2. Promoting a cooperative relationship with the client (respect, active listening, good communication) 3. Understanding the client's specific needs and concerns (his/her preferences, priorities) 4. Addressing the client's varied needs (paying attention to the whole person)
2. Understanding carers' role over time, including their need to balance caregiving with life/work demands	a. Understanding carers' caregiving situation and capacity b. Follow-up communication with/support for carers after the older person (care recipient) has been discharged from formal healthcare services (e.g., nursing/rehabilitation care at home) c. Carers' concerns about future changes in older person's needs/situation d. Taking into consideration carers' own needs and wishes when planning the older person's care	1. Promoting the client's active participation in making decisions about- and managing his/her health and social care needs 2. Promoting a cooperative relationship with the client (respect, active listening, good communication) 3. Understanding the client's specific needs and concerns (his/her preferences, priorities) 4. Addressing the client's varied needs (paying attention to the whole person)
3. Looking after carers' health and wellbeing; opportunities for respite	a. Advice/information for carers about taking care of their own health and wellbeing b. Carers' perceptions, efforts and concerns around taking care of their health and wellbeing c. Carers concerns about, and uptake of opportunities for respite	1. Promoting the client's active participation in making decisions about and managing his/her health and social care needs 2. Promoting a cooperative relationship with the client (respect, active listening, good communication) 3. Understanding the client's specific needs and concerns (his/her preferences, priorities) 4. Addressing the client's varied needs (paying attention to the whole person)
4. Carers' participation in decision-making and goal-setting	a. Carers setting goals regarding their health and wellbeing with professionals b. Carers creating plans for meeting their health and wellbeing related goals	1. Promoting the client's active participation in making decisions about and managing his/her health and social care needs 3. Understanding the client's specific needs and concerns (his/her preferences, priorities) 4. Addressing the client's varied needs (paying attention to the whole person)
5. Carers' perceptions of how they are treated by professionals	a. How carers are met and treated by health and social care professionals b. How professionals communicate with and listen to carers	2. Promoting a cooperative relationship with the client (respect, active listening, good communication) 3. Understanding the client's specific needs and concerns (his/her preferences, priorities)

		4. Addressing the client's varied needs (paying attention to the whole person)
Part 2: Elements of person-centered care		

1. Promoting the client's active participation in making decisions about and managing his/her health and social care needs
2. Promoting a cooperative relationship with the client (respect, active listening, good communication)
3. Understanding the client's specific needs and concerns (his/her preferences, priorities)
4. Addressing the client's varied needs (paying attention to the whole person)
5. Providing coordinated care