## WestminsterResearch

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**1**  **Introduction**

**2**  Carers often play a crucial role in an individual's treatment plan and emotional

**3**  support, including advocacy, encouraging help-seeking, and maintaining

**4**  engagement with services (Olasoji et al, 2017; Carlsen and Lundberg, 2018; Carers

**5**  UK, 2019; MacDonald et al, 2021). Many researchers have explored experiences of

**6**  those caring for individuals with mental health conditions (Olasoji et al, 2017; Liberati

**7**  et al, 2021; MacDonald et al, 2021), including depression (Scerri et al, 2019), bipolar

**8**  disorder (Wasley and Eden, 2018), psychosis (Sin et al, 2021) and eating disorders

**9**  (Yim et al, 2021). Additional challenges for those providing care to people with

**10**  mental health conditions are the comorbid behaviours that may occur, including self-

**11**  harm (SH) and suicidal behaviours (McLaughlin et al, 2014; O'Keeffe et al, 2021).

**12**  The existing research in this field suggests that individuals providing care to people

**13**  who carry out SH and/or enact suicidal behaviours could be at an increased risk of

**14**  experiencing poor well-being, unhealthy stress levels, and burnout (Byrne et al,

**15**  2008; Simpson et al, 2019; Hazell et al, 2021; Lascelles, 2021). Additionally, they

**16**  frequently worry about saying or doing the 'wrong thing' which may increase SH

**17**  (Reichardt, 2016; Ribeiro Coimbra and Noakes, 2021).

**18**     Recently, university students' mental health has been acknowledged as a

**19**  worldwide public health issue (Sharp and Theiler, 2018), with this cohort described

**20**  as a particularly 'high risk' group for experiencing mental health difficulties and

**21**  psychological distress (Larcombe et al, 2016; Browne et al, 2017; Hughes and

**22**  Spanner, 2019; Royal College of Psychiatrists, 2021), suicidal thoughts (Jasso-

**23**  Medrano and Lopez-Rosales, 2018; Mortier et al, 2018; Hazell et al, 2021) and up to

**24**  a third reporting SH during their studies (Borrill et al, 2009; Sivertsen et al, 2019;

25  Hamdan-Mansour et al, 2021). This increases demand on university counselling and

26  welfare services, as well as academic staff to offer well-being support (Hughes et al,

27  2018; Hughes and Byrom, 2019). In addition, many university students and family

28  members are providing 'informal'/unpaid support and care for their friends and loved

29  ones (referred to as 'carers' in the current article (Yeandle et al, 2017)), highlighting

30  the uniqueness of caregiving in a university setting (Laws and Fiedler, 2012; Byrom,

31  2019; Hazell et al, 2021; Edwards-Bailey et al, 2022).  In 2013, the Carers Trust

32  conducted research specifically focusing on the experiences of young adult carers

33  attending a UK college or university (N=101) (Sempik and Becker, 2014). Findings

34  highlighted difficulties in managing academic demands alongside caring roles, with

35  almost half (45%) reporting difficulties with their own mental health. Resultingly,

36  recommendations emphasised the need for universities to recognise and support the

37  specific needs of young adult carers (Sempik and Becker, 2014). However, our

38  understanding of the impact of these ever-growing demands on university support

39  services, as well as carers, is limited.

40

41  **Literature Review**

42  *Who are 'carers'?*

43  Estimates suggest that one in eight UK adults are unpaid carers, resulting in an

44  annual economic saving of over £132 billion (Carers UK, 2019). Since the start of the

45  COVID-19 pandemic in March 2020, these numbers have further increased, with

46  approximately one in four UK adults providing unpaid care (Carers UK, 2021). A

47  carer has been defined as *"anyone, including children and adults who look after a*

48  *family member, partner, or friend, who needs help because of their illness, frailty,*

49 *disability, a mental health problem or an addiction, and cannot cope without their*

50 *support…the care they give is unpaid"* (NHS England, 2021).

51    Aldridge and Becker (1993) first recognised the role of children and adolescents

52 under the age of 18 years. These individuals played a key part in providing

53 substantial amounts of unpaid care for family members with a range of physical and

54 mental health difficulties (e.g., Becker, 2007; MacDonald et al, 2021). The caring

55 continuum (Becker, 2007) captures the diversity of this, proposing the idea of *caring*

56 *about* vs *caring for* an individual. For example, a young person helping with basic

57 chores and cleaning would fall within the *'caring about'*, representing a 'normal'

58 involvement in caring activities. However, when this level of care increases due to

59 illness within families and households, young people move along the continuum to

60 *'caring for'.* Whilst earlier scholars recognised this group of young carers under the

61 age of 18, Becker and Becker (2008) noted that young adults, aged 18 to 24 years,

62 also play a crucial role in caring for family members, leading to the introduction of the

63 term *'young adult carer'.* This acknowledgement has encouraged researchers to

64 recognise the unique impact that this caring role may have on transition from

65 adolescents to early adulthood, particularly in relation to autonomy, employment, and

66 further education (Stamatopoulos, 2015; Boumans and Dorant, 2018).

67    Many individuals providing care do not identify with the label 'carer' and instead

68 view caring as part of being a parent, partner, or peer (Knowles et al, 2016).  This

69 group of 'hidden carers' can make it difficult to quantify the true number of people

70 providing care (Smyth et al, 2011; Waters, 2021). Despite making significant

71 contributions to the individual they are caring for, and society more widely, hidden

72 carers often struggle to access support for themselves (Onwumere et al, 2018;

73   Khan-Shah, 2020). In particular, young adult carers, and specifically those studying

74   at university, have been recognised as a unique group requiring greater support at

75   an educational level (Sempik and Becker, 2014). Given increased rates of isolation,

76   loneliness, and poor well-being amongst this group (Sempik and Becker, 2014;

77   Greenwood et al, 2018; Becker and Sempik, 2019), identifying contexts in which

78   young carers and unpaid care are under-recognised may allow for increased support

79   provisions to be developed.

80       As well as unpaid caring experiences, there are also paid professionals, referred

81   to as care workers for the purpose of this article, working in various caring roles

82   (e.g., allied health professionals, counsellors etc) across a range of settings. Whilst

83   research has frequently focused on the experiences of care workers in health and

84   social care, the voice of those working in educational, voluntary, and third-sector

85   settings is limited, despite playing a pivotal role in patient care (Harrison and Gordon,

86   2021). Within the education sector specifically, the increasing rates of poor mental

87   health among students, including those in caring roles, are placing rising demands

88   and pressures on care workers in university settings (Sempik and Becker, 2014;

89   Auerbach et al, 2018). However, the impact of these demands and professional

90   caring experiences within a university context has yet to be explored.

91

92   *Caring for mental health and SH in university settings*

93   Research suggests that young adults who SH are more likely to make disclosures to,

94   and seek support from, friends, family, and romantic partners rather than

95   professional care workers (Armiento et al, 2014; Rowe et al, 2014; Hall and Melia,

96   2022). Studies exploring student experiences of seeking professional support at

4

97   university, including counselling and well-being services, have highlighted key gaps

98   and limitations in existing provisions (e.g., availability and quality of care) (Baik et al,

99   2019). Resultingly, students engaging in SH often receive support from multiple

100  sources, including friends, family and other students (Edwards-Bailey et al, 2022).

101  This may present a unique group of *non-identified potential carers,* a term suggested

102  in the literature to describe individuals aged 15-24 who share a household with an

103  individual/s who may need support with their self-care, communication and well-

104  being (Hill et al, 2009).  Despite this, much of the university carer literature has

105  focused on identified young adult carers, particularly those caring for family

106  members, with little recognition of the broader role of caregiving among students

107  (Sempik and Becker, 2014; Byrom, 2019).

108     In recent years there have been several high-profile cases in the UK where a

109  university student has disclosed suicidal thoughts, mental health difficulties, or SH

110  within a university setting, but families were not informed due to data protection

111  legislation; in some instances these cases involved suicides (Murphy, 2019;

112  Coughlan, 2021; Megraoui, 2021). Initiatives have been introduced to encourage

113  collaboration between service users, professionals and carers in the UK (e.g., 'The

114  Triangle of Care' approach to mental health (Carers Trust, 2013)), with carers being

115  actively involved in the care of their loved ones. However, educational contexts such

116  as universities may be more challenging for implementing this approach due to

117  limited understanding of caring in this setting. As a result, those caring for university

118  students are often not involved or entitled to know what care, treatment or support

119  the person they are caring for is receiving. Students who are providing care may also

120  be managing their own difficulties and pressures of university life (e.g., coursework

121  and deadlines) (Sempik and Becker, 2014). Further, there is limited understanding of

122   the impact on professional care workers from the increasing demands on university

123   support services. To our knowledge, there is currently no literature specifically

124   exploring the role and experiences of those providing care to university students who

125   SH, warranting further research.

126   *Impact of the caring role: theoretical models*

127   Previous studies have highlighted key stressors experienced as a carer for those

128   with mental health difficulties, including negative reactions and stigma from family

129   members; carers feeling out of their depth or lacking adequate knowledge about the

130   individual's condition; and experiencing personal distress and social isolation

131   (Greenwood et al, 2018; MacDonald et al, 2021; Sin et al, 2021). Similar findings

132   have also been found among professional care workers in relation to poorer well-

133   being, burnout, compassion fatigue and increased stress (Cavanagh et al, 2020;

134   McCormack et al, 2018). Our understanding of why these negative impacts occur

135   may be explained in the context of effective coping and resilience. Transactional

136   models of caregiver stress highlight differing factors that influence the physical and

137   psychological health of carers and care workers. Individual characteristics of the

138   carer (e.g., gender), the needs of the individual they are caring for and the impact of

139   this on employment, relationships and finances, as well as the availability of social

140   support and coping mechanisms for the carer, have been suggested. More recently,

141   the mediating role of compassion on the negative impacts of caring has been

142   proposed by scholars, with the introduction of the caregiver suffering-compassion

143   model (Schulz et al, 2007; 2017). Compassion, defined as *'…a sensitivity to suffering*

144   *in self and others with a commitment to try and alleviate and prevent it'* (Gilbert and

145   Choden, 2013), involves emotional, cognitive and motivational processes. For those

146   offering a high level of compassion, if the individual they are caring for shows limited

147 reduction of suffering, these carers may be more likely to experience negative health

148 impacts. This highlights the potential influence of the caring continuum discussed

149 previously (i.e., Becker, 2007), with the lack of change in the individual's distress

150 having a greater impact on those with higher caring responsibility i.e., the *'caring for'*

151 end of the continuum. The need for future research to recognise caregiver

152 compassion is crucial for developing our understanding of caring, including ways in

153 which clinical practice and policy can be refined to support the needs of these

154 individuals (Schulz et al, 2007). To do so, exploration of feelings of love, concern,

155 interdependence, negative affect, distress, as well as desire and motivation to help,

156 is required (Murfield et al, 2020). While these compassion-related processes have

157 been explored in a family caring context, recognition of these factors among other

158 groups of carers and care workers is lacking. This highlights the importance of

159 research to better understand the role and experiences of people who provide care

160 and support to people who SH, with acknowledgement of wider systemic factors and

161 feelings of the carer that may influence the physical and psychological health of this

162 group. One avenue is to consider context-specific care and context-specific SH.

163     The present study aims to provide a novel insight into the experiences of people

164 providing care to UK university students who have self-harmed during their time at

165 university. Given the additional stressors of caring for people who SH, and the

166 negative impacts of carer burnout and compassion fatigue for both those providing

167 and receiving care, further research amongst carers/care workers in this setting is

168 required. We aim to understand the experiences of the different groups of carers in

169 universities, what caring means to them, as well as identify any areas in which they

170 may require further support when providing care specifically for SH.

171

172 **Methods**

173 ***Design***

174 A qualitative design, using in-depth, semi-structured interviews was adopted. All

175 participants experienced providing support for another individual who had self-

176 harmed during university. The Psychology Research and Knowledge Exchange

177 Ethics Working Group at the University of Westminster, made up of experienced

178 reviewers, granted ethical approval for conducting this research (*ETH1718-2337*).

179

180 ***Participants***

181 Twenty-four participants (19 female, 5 male) aged 18-55 years (M = 29.7, SD = 9.8)

182 were interviewed. The wide age range represents the broad spectrum of carers

183 within universities, with any individual with experience of providing support to another

184 individual engaging in SH during their time at university, either professionally, as a

185 friend, volunteer, colleague, parent, or in any other capacity included. Given the

186 limited knowledge of carers within a university setting and what this means to this

187 group, inclusion was deliberately broad, allowing participants to self-define as carers

188 based on their experiences. SH was defined as intentional self-injury or self-

189 poisoning regardless of suicidal intent (Hawton et al, 2012).

190     Recruitment took place through a variety of means. Individuals who had

191 previously taken part in an online survey conducted by the research team, exploring

192 SH during university, were able to leave their contact details to take part in further

193 research. Of those, individuals who indicated they had provided support for SH were

194 contacted and invited to take part in an interview. Participants recruited via this

195 method mainly consisted of friends and family carers, and those with both personal

196 and carer experiences of SH. In addition, posters calling for those with any

197 experience of supporting students engaging in SH were sent to all UK university

198 counselling and well-being services, student unions and key support organisations

199 (e.g., student minds, nightline). Adverts were also posted on social media (e.g.,

200 Twitter and Facebook). Nonprobability sampling techniques (i.e., convenience and

201 purposive) were thus used to recruit for interviews (Etikan et al, 2016).

202 Initially, a convenience sampling approach was taken, with participants contacted

203 on a rolling basis. After conducting several interviews, a spectrum of individuals in

204 university caring roles emerged (e.g., trained professionals, family, friends and those

205 who also had personal experiences of SH alongside caring for other students). Given

206 that the categories of carers did not fit with 'typical' definitions, a purposive sampling

207 technique was adopted to capture experiences in different geographical locations,

208 across the spectrum of university carers. Individuals based in UK locations different

209 to those where respondents had already been interviewed, and carers with limited

210 representation (i.e., friends and family) were selected. The final sample consisted of

211 three distinct groups of carers: professional care workers (N=10) (e.g., university

212 counsellors, mental health advisors and a GP); carers with no personal experience

213 of SH (e.g., friends/family members) (N=6); and carers with personal experiences of

214 SH (N=8). One professional care worker also had caring experience of a friend they

215 had lived with at university, and this dual role was explored. To maintain anonymity,

216 pseudonyms were assigned to all participants (see Table 1).

217

218 **Table 1**

219 *Participant pseudonyms and demographics*

220 *Insert Table 1 here*

221

### *Interviews*

Qualitative interviews were selected due to the extensive and under-researched nature of  providing support for student SH (Ritchie et al, 2013). Semi-structured interviews allow for an in-depth exploration of individual experiences, while ensuring researchers can maintain focused on the aims of the research (Low, 2013). The interview guide was developed through consideration of previous findings specific to SH (e.g., Wadman et al, 2018; Edwards-Bailey et al, 2022) and team discussions, with gaps in the existing literature on carers - e.g., the influence of compassion (Schulz et al, 2007) - used to tailor the interview schedule. Given  limited understanding of university caring roles, initial questions were designed to explore what the role meant and what this involved for the individual (see Table 2).

All interviews were audio-recorded and carried out by the first author (*LEB*), lasting an average of 44 minutes (range 31 – 65 minutes). *LEB* drew upon clinical experience of working psychologically with patients, families and multidisciplinary healthcare teams (MDTs), facilitating the interview process and promoting a relational focus (DeJonckheere and Vaughn, 2019). Due to the diverse sample and sensitive nature of the research, interviews were conducted using differing platforms: face-to-face (N=1), skype (N=4) and telephone (N=19). Use of different methods allowed for those with time constraints and those who did not wish to discuss their personal experiences face-to-face to take part in a less anxiety-provoking setting (Janghorban et al, 2014; Mealer and Jones, 2014).

In line with ethical approval, the study was performed in accordance with the Declaration of Helsinki. Informed consent was obtained in writing, prior to taking part and verbally during the interview. Pre-and-post interview scores of participants' emotional states were recorded using the Visual Analogue Scale (VAS). A debrief

247 and a list of supportive resources were administered on completion, with participants

248 offered £15 worth of vouchers for their time.

249

250 **Table 2**

251 *Semi-Structured Interview Schedule*

252 *Insert Table 2 Here*

253

254 ***Data Analysis and Rigour***

255 Interviews were anonymised and transcribed verbatim by *LEB*, with a reflexive

256 thematic approach to analysis (Braun and Clarke, 2006; 2021). Thematic Analysis

257 (TA) offers a flexible process, exploring detailed and rich data in an efficient and

258 systematic manner.  TA is not grounded to a distinct epistemological position but

259 enables patterns and commonalities across the dataset to be identified and

260 established into themes (Braun and Clark, 2006). In the present study, an

261 interpretivist position was taken.

262     Development of coding and themes were guided by the data using a semantic

263 and inductive process, following the 15-point checklist of TA (Braun and Clarke,

264 2006), with data stored in a locked cabinet on university premises. Participants were

265 offered the opportunity to review their transcripts prior to analysis. Reflections and

266 notes were made following each interview by the first author (*LEB*), providing deeper

267 context and opportunity for identifying researcher bias (Phillippi and Lauderdale,

268 2018). Initial hand coding was completed by *LEB* to allow for data familiarisation,

269 with all authors coding a sample of transcripts, establishing rigour and analyst

270 triangulation (Barusch et al, 2011; Noble and Heale, 2019). Any discrepancies were

271 resolved in team meetings, facilitating a greater level of understanding (Joffe, 2012),

272    resulting in final theme establishment with agreement from all team members. A

273    simultaneous process for coding and analysis was followed. The consolidated

274    criteria for reporting qualitative research (COREQ) were used in the present article to

275    provide a structured account of the qualitative process (Tong et al, 2007).

276

277    **Results**

278    Participants explored their experiences as carers and care workers in rich detail,

279    offering differing perspectives with regard to what being a carer meant for them and

280    how they offered support within their role. Reflections of personal development

281    during their journeys as supporters, with experience and understanding of SH often

282    growing along the way, were commonly discussed. Key similarities and differences

283    in perceptions of the impact of the caring role and experiences of accessing and

284    offering support for university students was highlighted. Four main themes were

285    identified, with two corresponding sub-themes (see Figure 1).

286

287    **Figure 1**

288    *Overarching themes and subthemes*

289    *Insert Figure 1 here*

290

291    ***The diverse role of a supporter: "I supported her in so many different ways"***

292    All participants reflected on what their 'role' in providing support for SH involved, with

293    the majority highlighting the significance of being present and listening.

294    Understanding and sense-making of being a carer were shaped by their personal

295    experiences of, or knowledge about, SH. Care workers and carers frequently

296 described offering practical support for the individual engaging in SH, however the

297 ways in which they did this and reasons for doing so differed between these groups.

298    Charles, who had supported his housemate at university, expressed a sense of

299 helplessness due to not knowing what his friend needed. As a result, he described

300 doing what he would personally find helpful, taking on a *'parental role',* often cooking

301 and helping them with day-to-day activities, e.g., getting to university. Karen, a

302 parent supporter, commented on the challenge of adjusting when her daughter

303 moved away to university, with her usual ways of caring (e.g., giving lifts and making

304 dinner) no longer being possible:

305

306    When she first moved away, we were worried … you know, I was concerned

307    as I couldn't do the usual things I would do to take care of her, she was

308    moving six hours away … it's almost like a different world when they are away

309    at Uni.

310

311    The need to keep the individual safe and promote recovery was frequently

312 mentioned by  participants and for carers this sometimes involved accompanying

313 them to medical appointments and emergency departments: *"I feel I supported her in*

314 *so many different ways and really pushed her to get better, like I took her to A&E a*

315 *few times."* (Kathryn, friend). For others, this related to encouraging support-seeking;

316 success was mixed, however.

317    If the individual did not feel ready to access support services, carers felt unsure

318 about what to do*: "She didn't want to get help, and I just felt like I didn't know what*

319 *more I could do, or where to go next."* (Ruby, friend/personal SH). Several friends

320 and family members described relief when the individual was able to access

321 professional support due to others being aware of the individual's SH. In contrast,

322 others felt *'pushed out'* due to a lack of awareness of what was being discussed and

323 limited recognition of the impact this also had on them:

324

325     ...my mum said that the first session she went to with my sister, they weren't

326     helpful at all. They seemed really unempathetic. Like not heard and feeling

327     like they didn't understand. They said to my mum that she couldn't be

328     included… (Neyo, sibling*)*

329 Conversely, Naomi had experienced joining her friend for several counselling

330 sessions which she felt had been a helpful and a positive experience for them both,

331 allowing her friend to *"openly talk about all her problems"*.

332     For care workers, the set-up of university support services impacted the way they

333 discussed their role, particularly the extent to which further support could be offered.

334 Due to limited resources and funding, several professionals mainly conducted

335 assessments and signposted to other services. Madison reflected that because of

336 this, her role felt more about *"prevention as opposed to directly curing"*. For others,

337 mainly university counsellors, their role was to provide longer-term therapeutic

338 support over numerous sessions. Mike worked as a university mental health advisor,

339 signposting students to external services. He explained this was more common for

340 those experiencing SH due to limited counselling capacity for *'risky'* students. This

341 led to him advocating for increased support within the university for these individuals.

342 However, when taking on a caring role for his housemate, this was about distraction

343 and spending time with them*:*

344

345      ...even driving around for half an hour, forty minutes, and just chatting about

346      crap is actually really helpful for her. And like coming home she was saying

347      how she felt so much better…

348

349 **The impact of providing support: "What about me?"**

350 Negative impacts resulting from providing care were commonplace, particularly

351 related to participants' health and well-being, and to their social and personal lives.

352 Some professional care workers reported feeling overwhelmed due to the lack of

353 resources and demands of the role (e.g., small teams caring for many students),

354 impacting their physical and mental health:

355

356      ...I mean, really, really challenging. I had some time off sick at Christmas

357      because I was just done. I just couldn't safely see anyone. I couldn't sleep, I

358      couldn't eat, I was just exhausted ... (Julia, university counsellor)

359

360 Managing the uncertainty and flexibility required (e.g., finishing work late) was often

361 detrimental for carers and care workers in relation to their social lives and

362 relationships with friends and family. Lydia (university counsellor) described feeling

363 *"tired and emotionally drained"* at the end of most days, preventing her from playing

364 with her children and struggling to engage in conversation with her partner. Most

365 carer groups mentioned feelings of shame and guilt. For professionals, this related to

366 not wanting to let their colleagues or students down, whereas for carers, it was about

367 wanting space and time for themselves:

368

369    ..there's that immense feeling of guilt that I can't do more. And there have

370    been times when I've wanted to leave the house in order to like to spend time

371    with some other friends who are my support...but I always feel guilty.. (Mike,

372    professional and friend).

373

374  When these feelings arose, establishing boundaries was considered crucial, acting

375  as a source of protection for their own well-being. Josephine (university counsellor)

376  explained that while the role impacts upon her to an extent, including missing

377  lunchbreaks and experiencing stress during the working day, she had learned to

378  *"develop ways of keeping working and home as separate as I can",* such as not

379  taking her work laptop home.

380      The ability to establish boundaries was more challenging for those living with the

381  individual (i.e., carers), who expressed a sense that physical proximity can mirror

382  emotional distance. This led to a conflict between wanting to help the individual while

383  recognising the need to protect their own well-being by creating distance, a common

384  theme for all friends and family. For Molly (friend), this resulted in her ending the

385  friendship entirely: *"I got to the point where I just couldn't have that in my life*

386  *anymore."* Others felt the supportive relationship was one-directional, with Katherine

387  (friend) sharing:

388

389    The main thing is that you're providing support to somebody, but then you

390    don't necessarily get that support back for yourself. And you feel a bit like your

391    problems aren't as bad as somebody else's. So, then you feel like you can't

392    share those things with them because they already have their own things

393    going on.

394

395     Several carers, specifically those with personal experience of SH, found their

396    caring role a cathartic experience, offering *'relatability'* and *'true understanding'.* This

397    however presented difficulties in relation to triggering their own SH due to discussing

398    difficult emotions and experiences. Leah explained that she'd often feel like a

399    *'hypocrite'* as she wouldn't follow the advice she'd given to her friend when in those

400    *'dark places'*.

401

402    ***Caring for the carer: "There just needs to be so much more"***

403    Most participants discussed needing support for their own well-being, as well as

404    greater knowledge of SH and a desire to connect with others in similar roles and

405    positions. The findings relating to the wider theme of carers' needs are presented

406    below across two subthemes.

407

408    ***"Knowledge is power"***

409    At the beginning of their careers, some professionals felt unprepared to support

410    students with SH due to limited training. Further, some recalled stigma arising from

411    senior colleagues' attitudes towards those who self-harmed, meaning SH was not

412    discussed with trainees and junior care workers. When reflecting on their current

413    insight into SH, several care workers felt that, even if they had discussed SH with

414    senior colleagues, this would probably have resulted in an inaccurate perception of

415    SH, due to many believing SH was simply 'attention-seeking'. Claudine (university

416    GP) shared: *"when I was a foundation doctor in A&E, no one paid people presenting*

417    *with SH any compassion. I even remember my consultant telling me to ignore them,*

418   *so they'd stop coming in".* For professionals in the present study, understanding of

419   SH often developed once working directly with SH:

420

421        I think my way of managing it then and supporting people was probably quite

422        different then to what it is now - or hopefully, anyway. (Eliza, mental health

423        advisor).

424

425   The need for more resources and information relating to SH was considered crucial

426   when responding to distress and providing support for SH, particularly among carers

427   with no personal experience of SH. Gaps in their knowledge about SH, for example,

428   the reasons why individuals may SH, what to say, or how to respond and when to

429   seek medical attention, were a real challenge. Most said more information and

430   resources specifically aimed at those in *'informal'* caring roles would be particularly

431   helpful, as they would potentially encourage those who SH to speak more openly:

432

433        I definitely did not have enough knowledge at all ... you automatically think

434        that when someone is cutting themselves that they are trying to end their life

435        …. If people do know about it, that would help people supporting, and also

436        help people say if they are doing it. (Naomi, friend)

437

438        Professional care workers also discussed the importance of information and

439   knowledge. Lydia (university counsellor) felt that a basic understanding of SH had

440   enabled her to empathise with what the student may be experiencing (e.g., *'distress'*

441   or *'feeling numb'*). Jenny (mental health advisor) noted the need for training to focus

442     on *'squashing'* stereotypes (including the common belief that individuals SH because

443     of wanting to end their lives) and the need to recognise the diversity of SH:

444

445         So learn the theory, learn the stereotypes, learn misconceptions, learn the

446         myths, learn what it actually looks like …. then, what are your solutions, what

447         are your strategies, what are your recommendations, what could you signpost

448         someone to, how do you have those conversations?

449

450     ***Care for the self***

451     A desire for personal support due to the responsibilities and impacts of the caring

452     role was frequently mentioned. For family and friends, resources aimed specifically

453     at strategies for promoting their own well-being while caring for others who SH was

454     important. Existing provision was described as limited: *"I just think there needs to be*

455     *so much more ... one worksheet on looking after yourself isn't going to hack it."* (Eva,

456     friend/personal SH). Several friends who were caring for other students at university

457     described a lack of awareness of how to access university support services,

458     questioning its usefulness:

459

460         …there would be advertisements for mental health and stuff in the uni, but

461         like, where do I actually go to talk to someone? Is it actually going to be of any

462         use to me? (Molly, friend)

463

464     Neyo (sibling) felt that offering different platforms for support, including face-to-face,

465     apps and websites may promote help-seeking, with less invasive platforms (e.g.,

466     apps) feeling more accessible, particularly initially. Professional care workers

467     discussed their support needs mainly in relation to personal and well-being support

468     for their role, given the demands of working in a university setting. Julia (university

469     counsellor) suggested that building *'rest days'* into her job plan would help to

470     manage this and prevent future sicknesses and absence. While peer support and

471     supervision were felt to be particularly useful, provision was inconsistent and

472     appeared to be dictated by service structure (i.e., leadership priorities and larger

473     staffing teams). Several professionals reflected that space for sharing new ideas and

474     research with others working in similar areas would be valuable:

475

476         I think time as a group would be really helpful, to have that space. I remember

477         once myself and my colleague had the chance to attend a conference and we

478         learnt so much, it was absolutely amazing. (Jenny, mental health advisor).

479

480     ***A supporters' perspective to accessing support during university: "Students***

481     ***are falling through the cracks"***

482     Based on their caregiving experiences, participants offered unique perspectives on

483     how support systems and services are structured in universities. Many felt adequate

484     services for students were lacking, citing limited sessions, staffing shortages and an

485     over-reliance on external support. This presented common challenges, with services

486     often not accepting university referrals due to students not meeting service criteria in

487     terms of severity. Several supporters said this resulted in students not receiving the

488     support they need:

489

490         It's like the people who are in too much of a crisis, to only be seen once a

491         week for six or twelve sessions, they aren't unwell enough to be sectioned or

492       to go to a crisis unit or anything, they really fall through the cracks …. There is

493       a lack of resources for those people who just need a bit more support. (Zoey,

494       university counsellor).

495

496  Professional care workers shared insights into how student support services are set

497  up, highlighting differences between institutions with regard to who students could

498  approach for support, the level of support available (e.g., number of sessions) and

499  divergence in referral systems and steps involved in accessing support (e.g.,

500  referrals and assessments). Several student carers felt that awareness of support

501  provision at university was insufficient, with advertised services only available at

502  specific times (e.g., mental health weeks), making it difficult for student carers to

503  navigate and signpost their friends. In addition, those with personal experience of SH

504  offered a distinct perspective on their encounters in using these systems. Maya

505  (friend/personal SH) described the requirement to share sensitive information with

506  multiple people: "*...you're having to tell all these people your problems and what

507  support you need ... you don't want to have to deal with all those steps to getting

508  eventually to the support.*"

509

510    Timely access to appropriate support was thought to be influenced by the

511  individual with whom the student chose to discuss their SH. Several supporters,

512  including professionals and friends, described students initially approaching course

513  staff (e.g., lecturers) due to a sense of familiarity. However, some professional care

514  workers were apprehensive about understanding of SH amongst lecturers and

515  tutors:

516

517        They develop a warmer relationship with one of their lecturers, and that will be

518        the first person they go to in some cases; we had some inappropriate

519        responses and that really shut the student down …. which just exacerbates

520        the problem. (Laurence, university counsellor).

521

522  Several supporters offered suggestions about what was needed to bridge this gap.

523  Claudine (university GP) commented ...*"I mean I completely believe that we need to*

524  *have a standardised approach to support for students."* She also noted, however,

525  that these issues can be hard to address due to funding challenges and regular

526  changes in service structures. Most professionals discussed the need for clearer

527  communication between services, either within the university, or more generally in

528  the community, and that recognition from senior levels within institutions is needed:

529

530        Whether it's about self-harming, suicidal ideation or so on ... communicating

531        that this isn't something to be ashamed of at an institutional level would carry

532        a lot of weight. (Julia, university counsellor).

533

534    Based on their experiences, friends and family offered less service-related insight,

535  instead suggesting greater awareness of resources available to students before

536  arriving at university, with a clearer pathway on where to access support. Those with

537  personal experience of SH shared first-hand accounts of the difficulty in knowing

538  where to go for help, speaking about having to *'jump through hoops'* due to services

539  being *'disjointed'*. There was a consensus that addressing these gaps would have a

540  positive impact both on the health and well-being of students who SH, and for those

541  offering 'informal' and 'professional' care.

542

**Discussion**

544 The findings of this study provide a nuanced, context-specific, understanding of the

545 experiences of those providing care for university students who SH. A broad

546 spectrum of care for SH was explored, revealing distinct groups of caregivers within

547 a university setting: professional care workers (e.g., counsellors, well-being advisors,

548 GPs);  carers (e.g., friends/family with and without personal experiences of SH). Our

549 research offers a unique perspective on the challenges faced: limited staffing and

550 opportunities for networking; inability to establish boundaries (living with the

551 individual, working longer hours than contracted); and inadequate training and

552 information specific to SH, with negative impacts on the well-being of professional

553 care workers and carers (burnout, guilt). Participants seem to agree that knowledge

554 and understanding of SH developed over time and through experience. The need for

555 greater awareness of SH, particularly among academic staff outside of formal

556 support pathways (lecturers, personal tutors), more training and awareness earlier in

557 professional careers, and better availability of information for friends and families

558 during their journey as a carer, was highlighted. Limitations and challenges of

559 student support provision, including limited number of sessions and difficulties with

560 referrals, require increased attention at an institutional level.

561 To provide effective support for others, individuals need to practise self-care and

562 ensure emotional availability (Glass and Rose, 2008). Most care workers/carers

563 spoke about a range of negative impacts on their well-being resulting from providing

564 support (reduced sleep and eating, social withdrawal). Previous research has

565 highlighted that carers and care workers face heightened emotional demands,

566 leading to increased stress and higher risk of burnout (Shah et al, 2010; Simpson et

567 al, 2019; Sin et al, 2021). Similar experiences in the present study may be indicative

568 of compassion fatigue and empathic distress, which is commonly experienced

569 among healthcare professionals and carers providing regular support for those in

570 distress (Figley, 2002), with negative physical and emotional impacts for carers and

571 those cared-for (Lombardo and Eyre, 2010; Smith, 2015; Hall et al, 2016). In some

572 studies, women report greater empathic distress than men (Smith and Rose, 2011),

573 perhaps reflecting the higher proportion of female participants in the presented

574 study. Research with a larger sample of male carers is needed to examine this

575 further.

576    The additional impact of the caring role reported by carers and care workers,

577 including cancelling social events and less time to complete university work, has also

578 been found in research on young adult student carers (Sempik and Becker, 2014)

579 and may be understood in the context of existing theoretical models. The

580 transactional model of stress suggests that those with limited social support and

581 coping strategies are at greater risk of experiencing negative impacts on physical

582 and psychological health (Murfield et al, 2019). Most carers described behaviours

583 and feelings indicative of high levels of compassion (feelings of concern, desire and

584 motivation to help). As those they were caring for were experiencing high levels of

585 distress and engaging in SH, this may have been interpreted as limited reduction of

586 suffering among those cared for. In line with expectations based on the caregiver

587 suffering-compassion model (Shultz et al, 2007; 2017), this would increase the

588 likelihood of empathic distress, in which the carer takes on the individual's distress

589 as their own (Smith and Rose, 2011). These findings may be best understood in the

590 context of a carer 'cycle'. Carers in our study who described taking direct

591 responsibility for the care of another's SH (presenting to A&E, taking them out for a

592    drive) often experienced a reduction in their own well-being if, despite their efforts,

593    the SH continued. The close proximity and shared environments of some university

594    carers, particularly friends (who described greater difficulty establishing boundaries

595    and maintaining personal space) and that many are young adults perhaps still

596    developing their own emotional regulation strategies, our findings may indicate an

597    increased risk of empathetic distress among these carers (Powell, 2018). This may

598    explain why professional care workers reported less personal impact arising from

599    continued SH as they could more easily establish distance and could access more

600    advanced training and supervision to address their own emotional distress. Further,

601    non-suicidal ideations and behaviours such as SH are more likely to occur when an

602    individual has increased need for emotion regulation (Kranzler et al, 2018), which

603    may explain why some carers experienced their caring role as triggering their own

604    SH.  Our findings suggest that greater resources aimed at increasing self-care and

605    employing strategies for managing guilt, burnout and worry for all individuals caring

606    for students are required.  One method may include compassion-focused

607    interventions - previous evidence supports a reduction in feelings of guilt and shame

608    (Sirois et al, 2019) – perhaps warranting further research exploring use of these

609    methods in a university setting.

610    In the UK, 'talking therapy' has been identified as an NHS 'blind spot' due to

611    inconsistent waiting times (Cooper, 2018) and private counselling is estimated to

612    cost £10-£70 per session (NHS UK, 2021).  Previous research has reported that

613    anxiety, depression and poor quality of life increase with treatment waiting times for

614    patients and carers (Reichert and Jacobs, 2018; Gagliardi et al, 2021). Further,

615    professional care workers in these systems are under increasing pressure, due to

616    extended waiting lists and demand, to evidence the effectiveness of the services

617    they provide (Randall and Bewick, 2016). This may offer insight into the increasing

618    pressures on carers and care workers reported in the present study, with limited

619    services and barriers to access commonly discussed.

620    While these factors impact carers' well-being, they may also deter carers from

621    accessing their own support. Burnout acts as a barrier to help-seeking among

622    professionals (Bearse et al, 2013), with lack of time and fear of leaving the individual

623    identified for carers (Ingleton et al, 2003; Fisker and Strandmark, 2007). When

624    exploring experiences of young student adult carers, almost half reported difficulties

625    with their own mental health. Despite this, most were not accessing support due to

626    feeling their difficulties were not recognised by their universities / colleges (Sempik

627    and Becker, 2014). Increased service provision for student mental health would allow

628    for greater student support, and also have potential to reduce negative impacts on

629    those in supportive roles.

630    A more nuanced finding in the current study was the challenge of supporting SH

631    specifically. Many care workers and carers experienced fear and worry about what to

632    say and how to respond, often related to limited training and information specific to

633    SH. These findings echo that of existing research among those providing support for

634    SH, emphasising the role of educational settings in enhancing knowledge of SH and

635    the need for more open dialogue to promote help-seeking (Hall and Melia, 2022;

636    Reichardt, 2016). This appeared to be more manageable for experienced care

637    workers and carers with personal experiences of SH, with relatability and a deeper

638    understanding having a cathartic role. This lends support to previous findings

639    exploring self-help groups for SH, with attendees reporting that the non-judgemental

640    space with peers was a positive experience, reducing isolation and providing a safe

641    setting for understanding and managing their SH (Boyce et al, 2018). Further

642 research exploring whether similar initiatives would help the student population, and

643 how they could be adapted (e.g., online) would be valuable.

644     Due to working in small teams, and/or in a specific university, opportunities to

645 connect with others working in similar settings and sharing of resources, was lacking

646 for some university care workers. Despite this, the majority felt this would be helpful,

647 providing space to learn from others and promoting collaboration. Research

648 conducted among schoolteachers found that those with little opportunity to interact

649 with other professionals in their area often felt isolated (Kim et al, 2017), leading to

650 burnout and poor job satisfaction, consequently impacting on student achievement

651 (Cooper and Alvarado, 2006; Johnson et al, 2012). When strategies to encourage

652 collaboration have been introduced, positive impacts on teacher and student well-

653 being and satisfaction have been reported (Jackson, 2013). While differences

654 between school and university settings are acknowledged, both at an individual and

655 systemic level, a more standardised approach to student support and greater

656 opportunities for professional networking may promote staff well-being, as well as

657 increased satisfaction among students about the support available to them while at

658 university.

659     Greater awareness among all university staff of mental health and SH specifically

660 has been called for (Oliver et al, 2016). Our findings provide further evidence of

661 students disclosing to tutors, with carers and care workers sharing accounts of

662 negative reactions (e.g., dismissal) when the individual they cared for disclosed their

663 SH. This has also been highlighted in research exploring suicidality among doctoral

664 researchers, reporting supervisors and university staff were ill-prepared and 'freaked

665 out' when discussing suicide (Hazell et al, 2021). Addressing this knowledge gap is

666 important, given that response at disclosure is particularly influential on future

667  support-seeking, specifically for those perceiving stigma, which is common among

668  those who SH (Williams and Mickelson, 2008). Further, students have also

669  suggested that if lecturers and tutors were more approachable and acknowledged

670  the difficulties experienced at university, this would positively impact on their well-

671  being (Baik et al, 2019). In the current study, some professional care workers

672  reported delivering mental health training, with a specific focus on SH and suicide

673  awareness, to both students and staff at their university to address this. Greater

674  understanding is needed of how, if at all, this lack of knowledge is being addressed

675  in universities. Hughes and Byrom (2019) explored academics' experiences of

676  managing student mental health, identifying key difficulties as boundaries,

677  responsibility and competence, in a study focused on staff teaching healthcare

678  courses. Further research, in varied academic disciplines, exploring the views and

679  experiences of lecturers and personal tutors regarding disclosure of mental health

680  difficulties, especially SH, would help establish how far they may also present as a

681  unique group of carers in the university context.

682  Our findings relate to an often overlooked group of non-identified potential carers

683  who are crucial in supporting university students. Previous literature has defined

684  non-identified potential carers and young adult carers as aged 15-24 years (Becker

685  and Becker, 2008; Hill et al, 2009), but it may be beneficial to adapt this definition to

686  ensure recognition of the full breadth of carers in university contexts. Carers in this

687  study were often attending university themselves, managing their own personal lives

688  and academic demands alongside their caring role; some also had personal

689  experiences of SH. This group commonly described 'just being there' for the

690  individual and 'listening' to their concerns, viewing their support as  part of their

691  relationship and/or friendship. These relationships have been recognised as

692  significant by students engaging in SH, allowing them to feel 'cared for', a factor in

693  reducing their SH (Edwards-Bailey et al, 2022). This vital role of unpaid care

694  alongside the demands of university life builds on previous work with young adult

695  carers at college and university (Sempik and Becker, 2014) that called for increased

696  provisions to support this "hidden army" of university carers. Our findings suggest

697  further exploration of different forms of caregiving, and how these may impact the

698  mental health and well-being of student carers is warranted, on a wider scale, and

699  may be crucial in the context of rising rates of poor mental health among university

700  students (Kumaraswamy, 2013; Duffy et al, 2019), established links between caring

701  with depression (Pinquart and Sörensen, 2003; Geng et al, 2018) and limited help-

702  seeking among this group (Sempik and Becker, 2014).

703

704  **Implications**

705  These findings have important implications for carers and professional care workers

706  in universities, as well as for students engaging in SH. While some participants

707  reported negative impacts on their own wellbeing and issues with the support

708  available, not only to those they cared for, but also for themselves, these

709  experiences suggest ways in which universities and organisations can focus their

710  attention. Supporting students experiencing difficulties with their mental health and

711  additional comorbid behaviours such as SH is crucial, however. Our findings

712  emphasise the need for supportive resources aimed specifically at those in caring

713  roles. Those from differing backgrounds and experiences will likely benefit from

714  tailored interventions (e.g., information about SH, establishing boundaries and

715  promoting self-care at home/in the workplace), which should be adapted to the

716  needs of different groups of carers in a university context. It is also important to

717    recognise that not all individuals may identify as a carer, and greater

718    acknowledgement and normalisation of needing support when providing care is

719    warranted. Findings of the current study have influenced the development of a

720    website aimed at those caring for student SH in higher education (Cherish Support,

721    2020). Additionally, recognition and attention at institutional and stakeholder level are

722    required; this can include promoting conversations about SH, more resources for

723    university-wide SH and suicide awareness training, and greater provision of student

724    and staff support.

725

726    **Limitations**

727    Most of the interviews conducted for this study took place via telephone. The

728    absence of visual cues can affect the richness of the data collected (Novick, 2008).

729    The team compared the transcripts of interviews conducted face-to-face and by

730    telephone and found no major differences in the depth of data collected (Sturges and

731    Hanrahan, 2004). As we aimed to collect data from a diverse sample across the UK,

732    use of telephone and skype interviews enabled broader participation than would

733    have been possible with face-to-face interviews.

734       The authors also acknowledge that since the study was conducted, support

735    systems may have altered within universities, both prior to and after the COVID-19

736    pandemic. The pandemic has significantly affected how universities in the UK and

737    worldwide are set up. This has included adjustments to online learning, with many

738    students unable to socialise or access face-to-face support. Global research on the

739    impact of the COVID-19 pandemic on student mental health continues to emerge,

740    revealing negative impacts on students' emotional and behavioural functioning (Cao

741    et al, 2020; Copeland et al, 2021). Negative health impacts on carers have also been

742 documented among those caring for family members with mental health difficulties

743 (Clark Bryan et al, 2020; Tuijt et al, 2021). Some of the experiences discussed in this

744 study require further exploration in the context of COVID-19 and university life,

745 including the significance of living with someone who may be engaging in SH, or

746 living at a distance and being unable to visit or see loved ones for long periods (e.g.,

747 during lockdowns). Many care workers have been providing support from their

748 homes and/or via online means, and research has yet to understand how this may

749 have impacted care workers' well-being, ability to establish boundaries and social

750 support. As the world continues to respond and monitor the pandemic, its

751 significance for these groups of carers and care workers, as well as for students who

752 SH, requires ongoing attention.

753

754 **Conclusions**

755 These findings highlight the diversity of carers and professional care workers within a

756 university context often consisting of a spectrum of individuals, from friends and

757 family to healthcare professionals and well-being advisors, within and outside

758 university settings (e.g., parents at home vs friends living with the individual). This

759 multifaceted dynamic presented challenges in accessing and delivering student care,

760 but highlighted the differing needs and shared experiences of those in university

761 caring roles. Coherent pathways for student support are vital to ensure those in need

762 of care can access it without delay or the risk of being missed by services. Greater

763 information around SH, recognition of the impact of the role and of those who may

764 be offering care in a university setting, as well as increased opportunities for

765 networking and sharing experiences of providing support are suggested.

766

771

772
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