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The multiplicity of caregiving burden: a qualitative analysis of families with prolonged disorders of consciousness.

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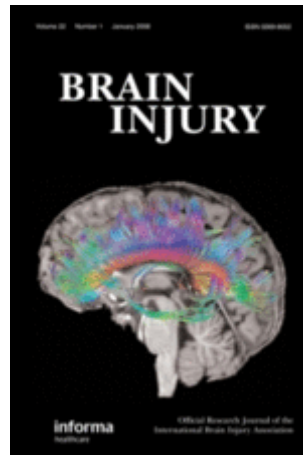
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Citation of this paper:

Laura E. Gonzalez-Lara, Sarah Munce, Jennifer Christian, Adrian M. Owen, Charles Weijer & Fiona Webster (2021) The multiplicity of caregiving burden: a qualitative analysis of families with prolonged disorders of consciousness, *Brain Injury*, 35:2, 200-208, DOI: [10.1080/02699052.2020.1865565](https://doi.org/10.1080/02699052.2020.1865565)

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The multiplicity of caregiving burden: A qualitative analysis of families with prolonged disorders of consciousness.

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|------------------|--|
| Journal: | <i>Brain Injury</i> |
| Manuscript ID | TBIN-2019-0463.R1 |
| Manuscript Type: | Original Paper |
| Keywords: | Caregivers, disorders of consciousness, roles, burden, priorities, qualitative |
| | |

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3 **The multiplicity of caregiving burden: A qualitative analysis of families with prolonged**
4 **disorders of consciousness.**
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7
8 **Abstract**
9

10 *Objective:* To understand the multiple and sometimes conflicting roles substitute decision
11 makers (SDMs) of individuals in a vegetative state (VS), minimally conscious state (MCS), or
12 with locked-in syndrome (LIS) perform while caring for a loved one and the competing priorities
13 derived from these roles.
14

15 *Methods:* We conducted semi-structured qualitative interviews using a constructive grounded
16 theory design. Twelve SDMs, who were also family members for 11 patients, were interviewed
17 at two time points (except one) for a total of 21 in-depth interviews.
18

19 *Results:* Participants described that caregiving is often the central role which they identify as
20 their top priority and around which they coordinate and to some extent subordinate their other
21 roles. In addition to caregiving, they participated in a wide variety of roles, which were
22 sometimes in conflict, as they became caregivers for a loved one with chronic and complex
23 needs. SDMs described the caregiver role as complex and intense that lead to physical,
24 emotional, social and economic burdens.
25

26 *Conclusion:* SDMs report high levels of burdens in caring for a person with a prolonged disorder
27 of consciousness. Lack of health system support that recognized the broader context of SDMs
28 lives, including their multiple competing priorities, was a major contributing factor.
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Introduction

In recent years, improvements in emergency medicine and critical care have resulted in more patients surviving severe brain injuries (1,2). Some of these patients will have a substantial functional recovery; some will recover, albeit with physical and cognitive impairments; yet another group will remain in vegetative state (VS) or minimally conscious state (MCS), following a period in coma (3). There are no definitive estimates on the world wide prevalence of VS, although it is estimated between 0.2 and 6.1 per 100 000 (4). Even though outcomes of patients in a VS have improved over the last twenty years (2), assessment of patients with disorders of consciousness (DoC) remains challenging (5) and the diagnosis relies on subjective interpretation of observed behavior. Patients with DoC are a very diverse population with variable cognitive and behavioral abilities as a result of a wide range of etiologies and comorbidities. The difficulty of the assessment, coupled with inadequate experience and knowledge due, in part, to the relative rarity of these complex conditions, contribute to an alarmingly high rate of misdiagnosis (up to 43%) in these patient groups (6–8).

These individuals are unable to make their own healthcare decisions, thus a substitute decision maker (SDM), usually a family member, will make these decisions on their behalf. In Ontario, Canada, the SDM is determined through a hierarchy specified in the Health Care Consent Act. Families usually play a central role in the care of patients with DoC as they become SDM, provide care, and endure the emotional strain that accompanies chronic illness and uncertainty about the future (9–12). The burden experienced by caregivers is unique as they are responsible for the patient's well-being yet do not get any direct feedback regarding the person's

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3 needs or preferences. Yet, we currently understand little about how to best provide support for
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5 them in the vital role they play as partners in the delivery of care.
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8 Qualitative studies conducted with families of patients in a VS have often focused on the
9
10 decision-making process, particularly around end of life care (13–17). Other qualitative studies
11
12 have explored social and psychological dynamics among family members and how their
13
14 interpersonal relationships are affected (18–20).
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17 This study is unique in that we sought to understand the burden experienced by families
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19 of individuals in a VS or MCS, specifically due to the multiple roles they play during the chronic
20
21 stage of the injury. Considering that caregiving occurs within the context of complex lives
22
23 characterized by multiple competing priorities and differing life stages, in this paper we report on
24
25 how their role as caregivers may conflict with their roles as spouses, parents, employees, and
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27 friends.
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33 **Methods**

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35 Our team undertook a modified constructivist grounded theory study to better understand the
36
37 experiences of family members of patients with DoC by focusing on their experiences and how
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39 they assigned meaning to these experiences through in-depth interviews. Data collection was
40
41 aimed at discovering and exploring a participant's experiences and analysis was aimed at making
42
43 sense of these experiences. Drawing on the principles outlined by Charmaz (21), our data
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45 collection and analysis were conducted concurrently, as we continuously reflected on the
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47 direction of the research, improvising methodological and analytical approaches throughout the
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49 process, and collecting enough data to understand the participants' points of view. Participants
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51 were family members acting as the SDM of patients who had participated in functional magnetic
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3 resonance imaging (fMRI) or electroencephalography (EEG) neuroimaging studies (22–26) on
4 serious brain injury at Western University; able to converse in English; caring for a patient
5 diagnosed as VS, MCS, or with locked-in syndrome (LIS) whose injury had occurred at least one
6 year prior. At the time of the patient’s participation in the neuroimaging studies, family
7 members were informed of this qualitative study and their informed consent was obtained if
8 interested (LG). Following informed consent, a time for a face-to-face or telephone interview
9 was arranged when ongoing consent was confirmed. We conducted semi-structured in-depth
10 interviews using interview guides, digitally recording and professionally transcribing the
11 interviews verbatim for analysis. Twelve family members participated in the interviews with a
12 total of 21 in-depth interviews. We interviewed most family members at two time points, before
13 and after receiving neuroimaging assessment results, which are identified as A and B
14 respectively throughout the quotes. There were 11 initial interviews with one having two
15 participants who shared the SDM role. There were 10 interviews in the second time point as one
16 participant chose not to participate. The University of Western Ontario Health Research Ethics
17 Board (REB) and the University of Toronto REB provided ethical approval.

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38 The core research team (LG, SM, CW, FW) coded several transcripts independently and
39 then met as a team 8 times to compare notes and share our interpretation. During these meetings,
40 we developed a coding framework with an experienced research assistant (JC), and then applied
41 it across all transcripts. This process required reflexivity as we challenged and supported each
42 other’s views and explored our individual standpoints, including our various disciplinary
43 backgrounds and stages of career (27). Our multi-disciplinary team consisted of a Research
44 Coordinator with a background in Engineering and Medical Biophysics (LG), a Postdoctoral
45 Fellow with Health Services Research expertise (SM), a Research Assistant with qualitative
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3 research management experience (JC), a qualitative sociologist (FW), a neuroscientist (AMO),
4 and a bioethicist (CW). We drew on our diverse backgrounds in order to help identify our own
5 biases and assumptions. We initially used *open coding* to organize the data into general concepts.
6
7
8 Then we used *axial coding* to compare relationships between codes (28). The codes were then
9
10 gathered into groups that shared similar meanings.
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17 Findings

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19 Twelve family members, eight females and four males, participated in the interviews for a total
20 of 21 in-depth interviews. The diagnosis of the patients, the SDMs' relationship to the patients,
21 time after injury and place of residence of the patient are summarized in Table 1. Most of the
22 interviewed caregivers were spouses or parents. Participants self-identified as the primary
23 caregivers and described in detail the multiple roles they needed to fulfil, the competing
24 priorities between these roles and the resulting burden. In their accounts, participants explained
25 the numerous roles they played by being the SDM, which also meant being the primary caregiver
26 to the patient, as well as advocate within the health care system, financial and/or legal
27 gatekeeper. In addition, most of these participants were also caregivers to other family members
28 and often the primary income-earner in the household. The caregiver role included tasks that
29 could be considered unpaid health care work since the needs of those with a severe brain injury
30 were often not adequately met by the health system. These complex and sometimes conflicting
31 roles appeared to have a significant impact on the participants' physical, social, financial and
32 emotional experiences.
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51 We have organized our findings around the core theme that caregiving is often the central
52 role which the caregiver identifies as their top priority and around which they coordinate and to
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3 some extent subordinate their other roles. We then describe the inter-related and sometimes
4
5 conflicting roles of: caregiver as unpaid health care provider, caregiver as advocate, caregiver as
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7 a member of a broader family system, caregiver as main financial supporter and gatekeeper, and
8
9 caregiver as member of the wider community. When these roles were in tension with each other,
10
11 participants were often unsure which role or responsibility to prioritize.
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13

14 15 16 17 ***Caregiving as central role around which others revolve*** 18

19 Participants often described their primary role as being that of caregiver. They often perceived
20
21 this as a duty, and described it as a central part of their identity. For example, spouses, who had
22
23 often been together for decades, explicitly identified their role of caregiver as a duty which they
24
25 often felt they had no choice but to assume.
26
27

28 *“I don’t think I have a choice, and not because I need to have a choice: he’s my husband*
29
30 *and that’s the commitment we have, we’re going to look after each other... I’m his wife, and*
31
32 *he’s stuck with me.” (P1, A)*
33
34

35 Furthermore, in some cases, this perceived duty of caring for someone who is behaviorally non-
36
37 responsive and unable to provide feedback regarding their needs or preferences, led the
38
39 caregivers to sometimes speak without making a clear distinction between themselves and their
40
41 loved one. For example, some participants often referred in the first-person when narrating
42
43 events actually related to their family member, identifying with them as a single unit:
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47 *“you know the dialysis patients, what they go through, and every alternate day there is a*
48
49 *dialysis and they have their in-between days doctors’ appointment, follow-up and all that. So*
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51 *I’ve had about, let’s say, 424 doctors’ appointments since 2004 until now.” (P4, A)*
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3 As SDMs, participants took on the responsibility to make many decisions on behalf of the
4 patient. They might share the decision-making responsibility and consult with other family
5 members in certain circumstances depending on how significant they perceived each specific
6 decision to be. For example, they might be comfortable making minor, everyday type of
7 decisions, but perhaps not those that involved a medical procedure.
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14 *“So when I say “I make decisions”, from the day-to-day perspective, like, you know, does he*
15 *need an acupuncturist, does he need a massage therapist, but those decisions I make, but if*
16 *there were other decisions such as, you know, for example at one point we need to decide*
17 *whether or not the [tracheostomy tube] should be put into him because he had an attack of*
18 *pneumonia, well, I made that decision but it was with the kids” (P1, A)*
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26 The burden of everyday care frequently fell on one person who would usually also make most
27 day-to-day decisions; it appeared that if anything were to happen to the primary caregiver there
28 often would not be anyone else ready/willing to take over. Participants spoke about being
29 overwhelmed by responsibilities and needs to meet, for their loved one with brain injury, as well
30 as other family members and how they felt the burden of all the responsibilities.
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37 *“What’s happened to me? ... It’s so draining doing what I’m doing... one hour of being with*
38 *him is equivalent to two hours of anybody else’s job.... It’s a grind, yeah... But somebody*
39 *has to do it.” (P2, A)*
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45 The additional and unexpected roles that an SDM suddenly had to take on also affected family
46 dynamics as the primary caregiver might need more emotional support. Even when the role of
47 guardian was shared, it was usually one person who took the lead on the practical aspects of
48 caregiving while another would take on an administrative role (e.g., when the SDMs were
49 parents, it would be common for one to take the lead on dealing with paperwork and payments
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3 while another one would deal with the hands-on care). For the person providing the everyday
4 care, usually a woman in our sample, this was often an emotionally draining process and this
5 person expressed a need to share their experience and challenges. The emotional burden of
6 hands-on caregiving was not always evident to the person performing the administrative duties,
7 and thus, this person might not be emotionally available to meet the other person's needs.
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15 *"it's almost like he doesn't want to hear about it. And I say, "Well, this is my job, this is*
16 *what I do," you know? (P2, A)*
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19 Most families identified time management as particularly challenging. Managing their daily lives
20 with added appointments was described as stressful and a challenge for their own wellbeing.
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24 *"Sometimes it is stressful, right, trying to manage a household and... trying to find time to*
25 *take care of yourself and your health is sometimes stressful also, right? And then you feel*
26 *guilt when you can't be there with [patient] because of your health... just trying to manage*
27 *being pulled in a lot of different directions." (P9b, A)*
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32 33 34 35 ***Caregiver as unpaid health care provider*** 36

37
38 SDMs spent many hours accompanying their loved one to various appointments and recognized
39 that the high needs of their loved one were not always met by the healthcare system. These might
40 include setting up feeding tubes, medications, and sometimes even transfers. Even though most
41 patients live in a hospital or extended care facility setting, with only two families caring for their
42 loved one at home (Table 1), family members would often feel responsible to provide some of
43 the care for their loved one themselves within the facility.
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51 *"when I'm at the hospital I do all the work, which means [I put this on myself] ... for*
52 *example, when I'm getting ready to leave for the day I actually put him back into bed*
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3 *myself... I get him comfortable... I get him all sorted out, and I put his [tube feeds] on when*
4 *I'm getting ready to leave... And I make sure that when I walk out of that room that I know*
5 *my husband's comfortable, okay, because now I need to know."* (P7, B)
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10 While participants appreciated the staff could provide some of this care and acknowledged some
11 of the work may have been self-imposed, they also needed to be assured that every aspect of
12 their loved one's care was addressed on a timely fashion. There were other aspects, such as care
13 coordination, which in some cases is provided by a paid employee (e.g., a case manager, social
14 worker, etc.), that would fall on family members. SDMs were able to recognize that the
15 accumulation of the work performed (e.g. coordination of multiple services, specialized
16 transportation, etc.) would be remunerated if done by a professional.
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26 *"I reckon if I actually added up my hours and, you know, charged out at 40 bucks an hour...*
27 *well, actually, probably more. I reckon I'm probably doing a \$60,000 a year job."* (P2, A)
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33 **Caregiver as advocate**

34

35 In addition to coordination and providing hands-on care, a role repeatedly identified by SDMs
36 was being an advocate for their family member with the injury. This role was perceived to
37 enhance the well-being of their loved one, from a medical perspective as well as in relation to
38 ensuring their comfort. At times it also reflected the family member's lack of trust in the
39 adequacy of the medical system to provide an appropriate level of care for their loved one.
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47 *"I don't trust them at all. They look at things when the patient is active and whatever, but*
48 *what about the passive patient? Here's a thing sitting there and it should not deteriorate as*
49 *the patient is going through this coma situation."* (P4, B)
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3 The lack of trust was often the result of past medical care experiences, including management of
4
5 chronic conditions:
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7
8 *“I guess I couldn’t really trust somebody anyplace after the experiences we had” (P6, A)*
9

10
11 *“Anyway, after half an hour she’s typing into the computer and she realized that she had*
12 *made the mistake and it’s the wrong address. And then it was returned back to [provincial*
13 *insurance] and then the number was cancelled” (P2, A)*
14

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16
17 *“Anyway, they wanted to hide the mistake that he did, the radiologist.” (P4, B)*
18

19 Alternatively, some participants described how they were able to build relationships with
20
21 healthcare providers, who could then also advocate for the patient.
22

23
24 *“And finding people that can also be an advocate.... Amazing when you’ve got people like*
25 *that on your side. That definitely helps” (P2, B)*
26
27

28 Recruiting the additional support, however, depended on the caregiver being comfortable
29
30 speaking out and identifying professionals who shared their views.
31

32
33 *“I did the best I could, and again every step of the way, every day and every time, I did not*
34 *hesitate to knock at the door of certain people who may provide me some extra mile.” (P4, B)*
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38 39 40 **Caregiver as members of broader family systems**

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42 Besides being a caregiver, advocate, and guardian for someone with prolonged DoC, SDMs also
43
44 needed to perform other roles and meet their other responsibilities such as providing for their
45
46 household, household chores, parental responsibilities, and spending time with other family
47
48 members. Participants described how these multiple roles could, at times, be in tension with each
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50 other which in some cases resulted in feeling negligent in the care of other family members.
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3 *“That’s what [father] and I had to remember... that we were also parents to three other*
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5 *children” (P2, A)*
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8 When participants were taking care of spouses, in addition to suddenly becoming caregivers,
9
10 they also described the burden of taking on family and personal obligations by themselves. Some
11
12 of these responsibilities might have been previously shared with the patient, for example,
13
14 parenting. Often the process of mourning, including anticipatory grief and complex grief,
15
16 impacted significantly on their other roles. They mourn the impending death of the patient and,
17
18 in some cases, sorrow lasts years of uncertainty with the caregiver unable to resume their own
19
20 life. For example, many expressed that visiting their loved one was draining as they mourned the
21
22 loss of a partner as the person they once knew.
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26 *“I work, and I have three children and, you know, I’m pretty-much on my own... it’s very*
27
28 *different when you’re alone as opposed [to] when you have a partner” (P5, A)*
29

30
31 *“I’ve been informed that it’s like the seven (sic) stages of grieving, and you go through this*
32
33 *regardless if the person’s passed away or that he is in the condition that he’s in” (P7, A)*
34

35
36 In other cases, the family unit might have been very small, consisting only of the person with the
37
38 injury and the caregiver. Thus, besides becoming caregivers, this also meant they had lost their
39
40 source of support for everyday life and even their motivation.
41

42 *“I’m pretty-much on my own, and the only help and support I get is with a female companion*
43
44 *that I have that tries to encourage me to eat something, because I’m not eating properly and*
45
46 *I’m lacking a lot of motivations to even do anything” (P10, B)*
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49
50 Another aspect of the emotional burden that had an impact on the family dynamics was the
51
52 feeling of powerlessness and, in some cases, even guilt for not being able to prevent the injury or
53
54 the primary caregiver not wanting to burden other family members.
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3 “[older brother] had extreme guilt when it first happened... because he’s the big brother, he
4 thought he should have been there” (P3, A)

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7 “I don’t want to bring any more burden to my son... he does have a lot of stress in his life...
8 Same with my daughter... I don’t want to... bring that to her” (P7, A)

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12 Finally, while participants felt the strain of competing priorities between being a caregiver and
13 fulfilling other family responsibilities, fulfilling other roles could also be rewarding; for example,
14 feeling motivated by taking care of younger children.

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17 “everything, every purpose that I’m doing, everything I’m trying to do is for my children...
18 I’m strong due to my kids.” (P5, B)

25 26 **Caregiver as main financial supporter and gatekeeper**

27
28 Participants often provided financial support for their families through paid employment, often
29 as the only remaining income-earner in the case of spouses. These participants had to find
30 balance between financial needs and professional goals, which sometimes would include making
31 difficult decisions.

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34 “*It was tough when I lost my job two and a half years ago. It was very tough... that’s when I*
35 *decided I was not going to continue my career, I was going to take a part-time job – just to*
36 *keep my sanity – but I was going to spend time with him.... now that I’ve gone back full-time*
37 *– because I have to pay bills – ... so I have to work.*” (P1, A)

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47 Trying to accommodate the additional responsibilities as a primary caregiver for patients
48 diagnosed with DoC had sometimes a negative impact on their other roles. For example, SDMs
49 would dedicate a considerable amount of time coordinating care, addressing concerns or at
50 appointments, which meant less time to attend to their other responsibilities.

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3 *“I can’t even have a full-time job because these are the problems that I have to deal with,*
4 *because no one’s in the hospital on the weekends, right? So I have to take time off during the*
5 *week, because after 5:00 there’s nobody there either. So these are the challenges you have to*
6 *deal with, so, you know, it’s just not easy to handle things like this.” (P1, A)*
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12 In addition to matters related to care cost and insurance, there are often financial decisions and
13 procedures that needed to be completed such as legal proceedings, which had financial
14 implications, as a result of the injury. These processes were often difficult to navigate without a
15 certain level of expertise.
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21 *“My husband is involved, too, and it was the two of [us] named on the power of attorney as*
22 *far as taking care of her physical and, you know, administrating her estate and things like*
23 *that, and her settlement... he was quite trained and versed on legal matters... he did a lot of*
24 *the financial end of it, you know, just the administration... dealt with the government and*
25 *stuff like that.” (P6, A)*
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33 Some patients had been independent adults in the workforce, some with property, and other
34 additional responsibilities such as caring and providing for their own dependents. Depending on
35 the patient’s stage of life, it was not always obvious who the long-term SDM and primary
36 caregiver would be. In more than one account, participants described a complicated process to
37 become the SDM. For example, a life partner might be the original SDM and this responsibility
38 might fall to other family members over time. This process could be stressful, painful and
39 conflictual. As one participant described it, this process of changing SDM “was awful, actually it
40 was a nightmare” (P2, A).
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51 The relationship between legal and financial responsibilities in caring for someone with such
52 severe injuries can be complex. For those patients that were already in the workforce and
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3 financially independent it might have meant that they were the primary income earner in their
4 households. In the case of young adults, even if they were independent, parents often became
5 suddenly and unexpectedly the SDM, which meant they also needed to plan for care in the long
6 term. Furthermore, depending on the cause of the injury, different types of insurance might have
7 been involved with a variety of benefits and paperwork to navigate. SDMs might suddenly find
8 themselves with a need for substantial and costly care while also navigating complex issues such
9 as insurance claims and tax credits.
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19 *“Our wills we’ve got re-written them twice since the accident... We have it set up that there*
20 *be provision for [patient] in our will, and there’s all sorts of tax implications... We also*
21 *have him signed up for the long-term disability tax credit that’s going on. He did receive a*
22 *settlement from his insurance company as if he had died... brain injury is not covered if you*
23 *have an injury. If you lose an arm and a leg, you know, you get \$25,000, or you lose an eye.*
24 *If you have brain injury it’s not covered.” (P2, A)*
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33 Even when the family situation settled into a routine, it became very difficult when there were
34 other unexpected medical needs among other family members that were complicated by ongoing
35 financial issues related to the patient with prolonged DoC.
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40 *“There was a lawsuit [that] went on for seven years... All the while we didn’t have enough*
41 *funds. We were dealing with no-fault insurance, just trying to stay alive... my husband fell*
42 *down a flight of stairs and had a very severe injury, was in the hospital for five months...*
43 *he’s never totally recovered... he lost his job, he couldn’t work anymore and everything, so*
44 *then we had to start over again.” (P6, B)*
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3 To address the financial burden, in some cases, caregivers needed to rely on external financial
4 support from different sources, including family members and government sources; not only for
5 additional services for their loved one, but to meet their own needs.
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9
10 *“I know financially how I coped... with the situation: my kids were very supportive in that*
11 *situation. You know, bills don’t stop, right?” (P4, B)*
12

13
14 *“I’m on ODSP (Ontario Disability Support Program) right now.” (P10, A)*
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17 18 19 **Caregiver as a member of the wider community** 20

21 Other social interactions were also affected as participants took on caregiving responsibilities.

22 While participants could express their own need for balance and having personal interests, they
23 found it stressful being aware of their own needs while not having enough time to address them
24 and were concerned about becoming isolated.
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31 *“I find sometimes it’s hard with outside interests... I do it but I find that sometimes [it] is a*
32 *strain... But we try and keep it balanced... it really takes a fine balancing act because you*
33 *don’t want to leave any of them out or turn down too many invitations or you just get left*
34 *out.” (P6, A)*
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40 Caregivers described a preference to remain involved in networks outside of their immediate
41 family, including religious communities. Participants often drew on these community resources
42 to meet their needs, to cope with unexpected burdens in caring for their loved ones and fulfilling
43 their own roles, including building strong social networks. For some participants, spiritual faith
44 was an important part of their coping strategies, while also providing the social network from a
45 community with shared beliefs.
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3 *“It’s been difficult. I mean, it hasn’t come easy, but I think it’s my faith, a lot of support –*
4 *family, friends – tremendous support. I think that has helped me in a very big way. But more*
5 *importantly I think it’s been my faith right from day one.” (P1, A)*
6
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9
10 *“We’ve got a very supportive church family and they help with visits... and my husband’s*
11 *been very loving and supportive in this.” (P8, A)*
12
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14
15 Nevertheless, even though many participants had strong support networks, participants
16
17 recognized that finding help could still be challenging.
18

19 *“there are very few people available who are flexible in their time. You know, either they’re*
20 *still working, obviously, or they’ve got other obligations.” (P2, A)*
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23
24 Support networks, flexibility and financial means, for those families who had them, were very
25
26 valuable to manage the burden of providing care for their loved one.
27

28 *“the company I work for is pretty flexible, so they understand the situation with [patient].*
29 *They’re been very supportive” (P3, A)*
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33 In another account a participant caring for her son described how her husband’s job as a high-
34
35 ranking executive at a company, allowed them to move quickly and make living arrangements to
36
37 be near their son.
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40 In some cases, new support networks were the direct result of their situation, and participants
41
42 appreciated having the opportunity to rely on others who fully understood their situation and
43
44 families could relate to each other.
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46
47 *“there’s another couple there that have a daughter pretty-well the exact same age as*
48 *[patient], somewhat the same condition, and when we go in the evenings we’d all of us sit*
49 *together and chit-chat a bit, nothing too personal and stuff, we just kind of chit-chat, so*
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3 *we're in the same... same experiences. And I[have] a couple [of] really, really good friends*
4 *that are like family” (P3, A)*
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8 For those who were able to rely on a strong support network, there seemed to be a change in
9
10 mind-set that resulted in deliberately looking for positive things. Alternatively, a coping strategy
11
12 might be carefully planning the timing to receive specific information related to the patient that
13
14 might be upsetting to avoid the risk of being overwhelmed by it.
15

16
17 *“I want to hear the good things but I don't want to hear the bad, right? So sometimes I don't*
18 *open [the report] ... like, it will be here for a month before I will open it. I mean, I have to be*
19 *having a good day before I do that... And there's always somebody, like, worse off. I have a*
20 *look around. She doesn't have cancer. She hasn't, I don't think, suffered like a lot of other*
21 *people... you just count your blessings where you can find them.” (P6, B)*
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30 31 **Discussion**

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33 Our participants provided rich descriptions of how caregiving was their main priority around
34
35 which they organized other roles and responsibilities. They also described in detail multiple
36
37 aspects of caregiving which could be as varied as providing emotional support, navigating the
38
39 health care system at the policy level, taking care of financial and legal issues. The process of
40
41 caregiving differed among participants according to their life stage, their involvement in their
42
43 communities, and their roles as employees, and members of broader family systems. In addition,
44
45 not all participants had strong family systems as a source of support available to them.
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50 In the literature, caregiving is often described as a singular activity/role and does not
51
52 consider the overall and often complex context in which caregiving is performed (29,30).
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54 Caregiving has also been largely conceptualized around the patient, not the caregiver themselves.
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3 Caregiver burden and coping has been largely understood as being about individual
4
5 psychological states rather than about life stages or contexts. In our study, those families with
6
7 greater access to material and emotional resources were also more successful in mobilizing
8
9 coping strategies. This suggests that coping is as much a function of structure as it is of
10
11 individual competency.
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15 The stories shared by the participants in our study highlighted the many unique features
16
17 of caring for patients diagnosed with DoC. These caregivers face a chronic state of uncertainty
18
19 with regard to the trajectory of their loved ones' illness and recovery and the extent of caregiving
20
21 involved. This is most often compounded by prolonged grief. In addition, these caregivers
22
23 describe providing care to a loved one without the benefit of feedback. Thus, the care they
24
25 provide becomes a prioritized responsibility that effects and often mutes how much they are also
26
27 to contribute to other relationships and other roles in their lives. In other cases, after a brain
28
29 injury, rehabilitation is expected to improve functional outcomes (31,32), particularly when
30
31 rehabilitation goals are person-centered and families and unpaid carers are part of the process
32
33 (33). However, even though outcomes (survival and recovery of consciousness) for patients in
34
35 VS have improved (2), and patients with moderate to severe brain injuries are likely to benefit
36
37 from comprehensive rehabilitation (32), recovery for patients in VS remains limited (34). This
38
39 often leaves caregivers of patients with prolonged DoC in a continual state of loss and grief
40
41 (12,35). The likelihood for recovery for patients with prolonged DoC is low, families are unable
42
43 to mourn for a death (36) and yet they grieve over a prolonged time (37). Participants in this
44
45 study referred to this state as mourning and going through the different stages of grief as family
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47 members care for a loved one for prolonged periods of time, often years, with substantial
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49 uncertainty not knowing how long they will be caregivers.
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3 In addition, caregivers often felt a sense of duty, leaving them no choice as to the extent
4 of care they were called to provide, resulting in a sense of loss of control over their lives.
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6 Spouses in this study expressed they often experienced a sense of duty concurrently with a
7
8 confusing sense of mourning similar to what has been previously reported by Hamama-Raz *et al.*
9
10 (19). There are few resources available to support caregivers of patients who have survived
11
12 critical illness, and in the case of patients with prolonged DoC, with considerable needs. Lack of
13
14 resources and sense of control over life has been reported to be associated with poorer mental
15
16 health outcomes (38). Caregiving has been previously described as a lonely experience (39) and
17
18 hopelessness, in particular, has been associated with a higher burden (40). Regardless of the
19
20 etiology, it has been recognized that providing care for a family member following a severe
21
22 injury results in emotional, physical, social, and financial strain (19,41–43). In particular, anxiety
23
24 and depression have a detrimental effect on the mental and physical health of caregivers of VS
25
26 and MCS patients (44).
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33 Participants in this study described how the caregiver role often included taking on care
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35 coordination responsibilities, which is crucial to address gaps in care that exist within the health
36
37 care system. Care coordination, a role sometimes fulfilled by a case manager or social worker,
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39 brought additional responsibilities beyond providing hands-on care, such as appointment
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41 scheduling, transportation arrangements, etc., which required a significant time commitment and
42
43 made balancing competing demands among various roles challenging.
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47 The burden of multiple roles and how family dynamics are disrupted as caregivers
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49 balance different responsibilities was previously reported by Giovannetti *et al.* using a battery of
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51 questionnaires with a large cohort study in Europe (46). In our study, participants provided a
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53 detailed account through in-depth interviews of their caregiver role as sometimes being
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3 overwhelming and draining, which made them feel powerless as other family members and
4 friends moved on with their lives. Balancing competing priorities was challenging in part as
5 responsibilities shifted and family dynamics changed following an injury. For instance, in the
6 case of spouses with young families who, in addition to becoming primary caregivers for the
7 partner with brain injury, they simultaneously lost a companion to share parenting
8 responsibilities with. To add to this burden, there may not be emotional support available for
9 children affected by a parent sustaining a traumatic brain injury (TBI) (47) or for the caregiver
10 (48). Family dynamics were also altered in the case of parents caring for an unresponsive child
11 even though decisions would usually be made as a couple. It has been previously reported that
12 caregivers, for critically ill patients and specifically VS/MCS patients tend to be primarily female
13 (38,46). We also found that the routine care in these cases would have distinct divisions with one
14 parent, usually the mother, providing daily, hands-on care (e.g. transport, transfers, feedings)
15 while the other one parent, usually the father, took on administrative duties (e.g., legal, financial
16 issues). This division of duties sometimes led the caregiver to feeling isolated as they perceived a
17 fragmentation of the family in this job division that impacted their personal relationships and
18 overall family dynamics.

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40 As members of the community, participants in our study provided detailed descriptions
41 on their own social networks as a crucial component to managing the burden of caregiving e.g.,
42 spending time with their friends or faith communities. They described the need to balance their
43 role as caregivers while also remaining engaged members of their community and expressed
44 concern that if they did not participate in some community activities they would eventually be
45 excluded. A poor social network, in addition to injury severity, was previously identified in a
46 European cohort as a predictor of burden in caregivers of patients with severe TBI. This held
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3 true, even when the patient had some functional recovery and was no longer considered VS or
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5 MCS (48,50). Coping strategies have been recognized as an important aspect to minimize the
6
7 burden caregivers face (49) and these need to be developed to reduce the psychosocial burden
8
9 that caregivers of patients with prolonged DoC may experience (51). TBI survivors and
10
11 caregivers also need mental health services as they are impacted by the increased responsibilities,
12
13 with competing demands on their time (52), particularly in the case of family members taking
14
15 care of someone in a VS (53). Relationships within social networks can be particularly affected
16
17 when the patient lives in a long term facility, which may exacerbate the feeling of isolation for
18
19 the caregiver who tries to balance personal responsibilities with obligations to his or her family
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21 member (46,54).
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26 Oyesanya *et al.* recently reported on the need to understand more about what families
27
28 experience, following moderate to severe TBI, so that providers can better meet their needs, and
29
30 address gaps in expectations and actual services (55). Family members need support regardless
31
32 of whether they are providing daily care or not. Even when services do exist, families and
33
34 healthcare professionals may be unaware of them (56). Our findings highlight an urgent need to
35
36 improve the support family members receive by centering services around them and their
37
38 multiple and varied experiences and acknowledging the many aspects of caregiving in which
39
40 they may be engaged. Services should also be tailored to differing life stage and access to
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42 resources.
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47 While there were some socioeconomic differences in our sample and the availability of
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49 support networks, most participants were also residents of Ontario and had access to provincial
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51 healthcare specific to the Canadian context. We acknowledge that this study has some
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53 limitations, including the size of our sample being relatively small. By using a sample of
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3 convenience from those participating in imaging studies our study may be subject to a selection
4 bias as these were participants who had significant knowledge of recent research and the
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6 resources to pursue it. The majority of participants were female and caregivers of individuals in a
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8 VS. Time spent as caregivers varied between subjects, sometimes for decades. The time between
9
10 interviews also varied. Nevertheless, we were able to explore the interactions between multiple
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12 roles with competing priorities, the burden experienced and coping strategies through in-depth
13
14 interviews. Our findings converge with those from studies in other countries and with different
15
16 methodologies in the scope of the burden caregivers face and the need for support in different
17
18 areas at various times. All participants expressed being overwhelmed at different stages due
19
20 mostly to limited time to manage the competing priorities from their different roles and limited
21
22 resources. Social networks were identified as an important part of their coping mechanisms to
23
24 feel less isolated and able to ask for help. When developing interventions and strategies to
25
26 improve care, it is important to focus not only on the patient, but on the whole family and their
27
28 particular contexts for providing care.
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Conclusion

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39 SDMs of individuals in a LIS, MCS, or VS play many roles and they report high levels of
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41 burdens in caring for a person with a prolonged DoC. Lack of health system support that
42
43 recognized the broader context of SDMs lives, including their multiple competing priorities, was
44
45 a major contributing factor. Their roles included caregiver as unpaid health care provider,
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47 caregiver as advocate, caregiver as a member of a broader family system, caregiver as main
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49 financial supporter and gatekeeper, and caregiver as member of the wider community. When
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51 these roles were in tension with each other, participants were often unsure which role or
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responsibility to prioritize. Tailored resources and support for caregivers are necessary as coping depended on access to material and emotional resources.

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Table 1. Participants.

| <i>Participant</i> | <i>Relationship to patient</i> | <i>Time after injury</i> | <i>Place of residence</i> | <i>Diagnosis</i> |
|--------------------|--------------------------------|--------------------------|---------------------------|------------------|
| P1 | Wife | 5 yrs | Hospital | VS |
| P2 | Mother (son) | 4 yrs | Long term care facility | MCS |
| P3 | Father (son) | 17 yrs | Long term care facility | VS/MCS |
| P4 | Husband | 1 yr | Hospital | VS |
| P5 | Wife | 3 yrs | Hospital | VS/MCS |
| P6 | Mother (daughter) | 22 yrs | Home | VS |
| P7 | Wife | 1 yr | Hospital | LIS |
| P8 | Mother (son) | 1 yr | Hospital | VS |
| P9a&9b | Father (son)* & Sister | 1 yr | Hospital | MCS/EMCS |
| P10 | Father (son) | 3 yrs | Long term care facility | VS |
| P11 | Mother (daughter)* | 2 yrs | Home | VS |

* Only participated in interview A, before receiving neuroimaging assessment results.

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