

ORIGINAL ARTICLE

“Walking a tightrope”: A grounded theory approach to informal caregiving for amyotrophic lateral sclerosis

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Funding

This project on ALS informal caregivers' needs is funded by the Swiss Academy of Medical Sciences (SAMS PC 21/17).

Abstract

Informal caregivers, mainly family members and friends, provide supportive and palliative care for people with amyotrophic lateral sclerosis (ALS) during their terminal disease course. Informal caregiving for people with ALS continues towards palliative care and end-of-life care with the progression of the disease. In this study, we provide a theoretical understanding of informal caregiving in ALS utilising 23 semi-structured interviews conducted with informal caregivers of people with ALS (pwALS) in Switzerland. Due to the expected death of the care recipient, our grounded theory approach outlines informal caregivers' caregiving work as an effort to secure a balance amongst different caregiving activities, which feed into the final stage of providing palliative care. Overall, our theoretical understanding of ALS informal caregiving work encompasses the core category 'holding the balance' and four secondary categories: 'Organising support', 'being present', 'managing everyday life' and 'keeping up with ALS'. The core category of holding the balance underlines the significance of ensuring care and normalcy even as disease progresses and until the end of life. For the informal caregivers, this balancing act is the key element of care provision to pwALS and therefore guides decisions surrounding caregiving. On this understanding, those caregivers that succeed in holding the balance can provide care at home until death. The balance is heavily influenced by contextual factors of caregiving, for example relating to personal characteristics of the caregiver, or activities of caregiving where the goal is to ensure the quality of life of the pwALS. As there is a heterogeneity of speed and subtype of progression of ALS, our work accounts for multiple caregiving trajectories.

KEYWORDS

amyotrophic lateral sclerosis, family, grounded theory, informal caregiving, palliative care

1 | INTRODUCTION

Amyotrophic lateral sclerosis (ALS) is a complex multisystem progressive neurodegenerative disease of upper and lower motor

neurons leading to muscle weakness (Conroy et al., 2021; van Es et al., 2017). Amongst the neurodegenerative disorders, ALS is the most rapidly progressing (Kiernan et al., 2021). Progressive muscle weakness causes dysarthria, dysphagia and dyspnoea with death

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from respiratory impairment after a median of 2–4 years (Del Aguila et al., 2003), but 10%–20% of ALS patients have a survival longer than 10 years (Chiò et al., 2009). ALS is caused by genetic and environmental factors (Al-Chalabi et al., 2014). Whilst ALS primarily affects the motor neurons, 30%–50% of people with ALS also have cognitive, emotional and behavioural impairments (Giordana et al., 2011). Depending on the type of ALS, different voluntary muscle groups are affected and lead to different clinical presentations (Bendotti et al., 2020; van Es et al., 2017). In most patients, the onset of ALS is between 50 and 70 years of age (Caroscio et al., 1987; Liu et al., 2014). The prevalence of ALS in Europe and in people with European descent has been estimated at 22–30 cases per 100,000 people and male patients are more commonly affected (Logroschino et al., 2010) with a ratio of 1:3 from female to male patients (Manjaly et al., 2010). Currently, multidisciplinary care remains the bedrock of disease management (Talbot et al., 2018).

Given the incurable nature of ALS, any care provided to people with ALS (pwALS) can from diagnosis be understood as palliative according to the definition by the World Health Organization (Sepúlveda et al., 2002). Effects of this systemic severe neurodegenerative condition extend far beyond the physical weakness and mobility issues commonly associated with ALS (Brizzi et al., 2020). ALS is often described as an illness affecting the whole family, as it takes its toll not only on pwALS but also on their immediate social environment (Cipolletta & Amicucci, 2015; de Wit et al., 2019). Moreover, informal caregivers, mainly family members, provide supportive and palliative care throughout the ALS disease course (Aoun et al., 2013; Conroy et al., 2021). During the caregiving period, informal caregivers experience different needs (Aoun et al., 2013; Oh & Kim, 2017; Poppe et al., 2020; Schischlevskij et al., 2021), for example for external support and assistance, psychological-emotional support and patients' acceptance of outward services (Antoniadi et al., 2021; Galvin et al., 2016, 2018; Mockford et al., 2006). The burden of informal caregiving is mediated by the physical and cognitive impairment of the pwALS (de Wit et al., 2018; Gluyas et al., 2017).

For informal caregiving in ALS, Lerum et al. (2016) identified five lines of work: *immediate care work*, *seeking information and clarity*, *managing competing obligations*, *maintaining normality* and *managing external resources and assistance*. Their study follows a sociology of work of informal caregiving for and coping with chronic illness in the tradition of Corbin and Strauss (1985). This methodological tradition is characterised by 'intense interest in understanding and analyzing how dying, pain, chronic illness, and illness in general are perceived and handled by staff members, relatives, and patients, how they become an object of work and require a sophisticated organization of work' (Riemann & Schütze, 1991, p. 333). For chronic illness, Corbin and Strauss (1985) have highlighted three key works: *illness work*, *everyday life work* and *biographical work*. Instead of focussing on illness experience, the authors used the concept of *illness trajectory* that 'refers not merely to (a) the course of an illness, but (b) to all the related work, as well as (c) the impact on both the workers and their relationships that (d) then further affect the management of that course of illness and the fate of the person who has it' (Corbin & Strauss, 1985,

What is known about this topic and what this paper adds?

- Informal caregiving for people with ALS is a demanding and variable process
- Using a grounded theory approach, informal caregiving in ALS is seen as a constant endeavour to hold the balance between different activities (organising support, being present, managing everyday life and keeping up with ALS)
- This theoretical understanding allows for an anticipative resource-oriented as well as a reactive deficit-oriented approach to informal caregiving in ALS

p. 225). However, this trajectory model does not fully explore the work of informal caregiving, especially in an expected death model, such as in ALS (Penrod et al., 2011). Adding to the theoretical understandings of caregiving in end-of-life circumstances and in ALS in general, we seek to depict informal caregiving for pwALS as their disease progression continues towards palliative care and end-of-life care. Our analysis is grounded in 23 semi-structured interviews conducted with informal caregivers of pwALS. More specifically, our research also addresses what lines of work informal caregivers perform to enable caregiving at home – and how the caregiving trajectories differ according to place and time of death.

1.1 | Methods

We used a qualitative approach based on the constructivist grounded theory method (Charmaz, 2006) which focused on reported processes and actions of informal caregivers to build a theoretical understanding of informal caregiving in the context of palliative care for pwALS. Key to this approach were intensive line by line initial coding, memo writing, focused coding and the definition of categories.

1.2 | Sample

Our sample was comprised of 23 informal caregivers, mostly family caregivers, with an age range from 28 to 74 years. From the family caregivers, most were spouses or daughters of pwALS (see Table 1). Informal caregivers were recruited purposefully through ALS centres in German speaking parts of Switzerland, through patient initiatives (Verein ALS Schweiz), peer contacts of former caregivers and via snowball sampling. Theoretical sampling, whilst an important pillar of a grounded theory method (Charmaz, 2006), was not possible as the participants for the phenomenon under study were not widely available. Hence, we could not choose participants along theoretical lines. According to Charmaz (2006), theoretical sampling means

TABLE 1 Demographic data

Total number of caregivers	$n = 23$
Gender	18 female, 5 male informal caregivers
Age of caregivers	range 28–74; mean 56, 76 years
Age range of people with ALS living with current caregivers	range 48–70; mean 57, 67 years
Relationship to the pwALS	11 wives, five husbands, six daughters and one female friend of people with ALS
Year of ALS diagnosis	2018–2010: $n = 19$ 2010–2000: $n = 3$ Before 2000: $n = 1$
Still working	61% yes, 39% no

'seeking and collecting pertinent data to elaborate and refine categories in your emerging theory' (p. 96). As this was not possible with this sample, our grounded theory approach is similar to a grounded theory using secondary data (Andrews et al., 2012; Whiteside et al., 2012). Our approach concurs with the description by Andrews et al. (2012) who write that 'although it was possible to move back and forth between the transcripts and to theoretically sample for emerging ideas and concepts, it was not possible to sample new participants, events or other sources of data to inform the emerging categories and their properties' (p. 17). Our interviews resulted in rich data and densely coded text. The focused coding resulted in a thick description of the material and was guided by theoretical coding. The procedure of data coding was iterative (see below *Data analysis*).

Participants contacted the interviewers via phone, mail or email after having heard of the study through ALS centres, patient initiatives or peer contacts. The interviews took place between 2018 and 2020 mainly in person in the participants' homes to accommodate time and caregiving constraints. Interviews were conducted and audiotaped after all participants had provided written informed consent. Interviews were between 30 and 120 min in length. Each participant was interviewed only one time. Interviews were transcribed verbatim in Standard High German using MAXQDA (VERBI, 2020).

The interviewers were a female physician (MD) working in general practice and a male clinical psychologist (MSc) working in the academic setting. Both were native Swiss German and German speakers, had prior practice in conducting qualitative research interviews or analysis and were repeatedly trained in qualitative data collection. The first four interviews served as a pilot for the semi-structured interview guide and the interviewers' interview skills, which were supervised by a senior researcher. The interview guide comprised of open-ended questions regarding practical supportive needs during the caregiving trajectory, difficult situations caregivers had experienced, advance care planning and end-of-life experiences as well as the time after bereavement. The informal translation of the interview guides can be found in the supplementary material (Appendix A: Interview guides). The interviewers did not have any prior relationship to the research participants nor did the participants have specific knowledge about the interviewers apart from general information about the project.

1.3 | Data analysis

We performed coding in parallel to data collection. As the goal was to gain a theoretical understanding of the process of caregiving, codes were written in the gerund form. Coding was an iterative and interactive process moving between different codes and transcripts. Initially, five interview transcripts were coded by hand in teams of two to three coders (six coders overall) to satisfy rigour and to get a common understanding of the initial coding process. After initial coding, initial codes were coded in a focused manner. Whilst focused coding, memos were written for the category building part of theory building. Together with the focused codes, memos were used to construct five categories of the informal caregiving process in the ALS disease course, especially with regard to caregiving in palliative and end-of-life care. For examples of codes and memos in a codebook, see Table 2.

In category building, abductive reasoning was key, meaning that the focused codes were best explained by the built category. One of these categories cut across the four other categories and was constructed as the basic social process which 'can be applied to varied substantive areas' (Charmaz, 2006, p. 92). Generally, this basic social process is defined by its 'pervasiveness, full variability and change over-time' (Glaser & Holton, 2005, p. 9). Theoretical saturation was monitored during the initial and focused coding phase and assumed when no new focused codes could be constructed. Finally, categories were translated from German to English.

2 | RESULTS

Due to the expected death of the care recipient, our grounded theory approach outlines informal caregivers' work as an effort to secure a balance amongst different caregiving activities, which all feed into the final stage of providing palliative care. This balance is characterised by the core category *holding the balance*, an organising element to the other categories. Overall, our theoretical understanding of ALS informal caregiving work encompasses the following four secondary categories, *organising support*, *being present*, *managing everyday life* and *keeping up with ALS*.

TABLE 2 Codebook

Category	Focused codes (examples)	Initial codes (examples)	Theoretical memos on focused codes (examples)
Holding the balance	<ul style="list-style-type: none"> Being employed Getting paid sick leave Having a good relationship with pALS Burdened by illness situations Noticing limits of care during the disease course Being overburdened Getting support through a large team Getting peer support Looking for information 	<ul style="list-style-type: none"> Care gave closeness Doing what the ill person wants because they are ill Negotiate the situation with pALS Cannot change the situation Discuss everything with pALS Being burdened by double caregiving role, mother and wife Becoming a contact person for pALS Knowing pALS well Drawing strength from the relationship with pALS 	<ul style="list-style-type: none"> pALS did not recover from a surgery causing rapid adjustment 'Everything is burdening' and the impossibility to hold a balance Reduction of work hours was not possible, using vacation days to care pALS is dealing well with ALS and is happy to be able to stay at home
Organising support	<ul style="list-style-type: none"> Getting support from specialised nurses Having assistants Contact patient organisation Being supported by specialised neuromuscular centres Having privately paid help for support Needing more support with progression of ALS 	<ul style="list-style-type: none"> Recommending holistic support More support would have been available Having someone to talk to Needing to look for support Recommending getting support early Having difficulty integrating support into everyday life Needing financial support Needing moral support Wishing more support from friends and colleagues Having respite support Not getting any support offers Having help with chores 	<ul style="list-style-type: none"> Psychological support can be important if the timing is right and visits at home are possible Home visits are important Early death of pALS led informal caregivers to have no further need for support Recognition of caregiver's work is important to them
Being present	<ul style="list-style-type: none"> Managing attendance to the person with ALS Not taking over care on one's own completely pALS is never alone 	<ul style="list-style-type: none"> pwALS is never alone Someone is always present in the case that pwALS falls pwALS wants the caregiver to be present Having round-the-clock care Time management is difficult Being there round the clock so that pALS does not have to be anxious pALS should not be alone Flexibility is needed Still being able to go shopping Recommending to not isolate yourself Not taking over care primarily 	<ul style="list-style-type: none"> Family constellation (single child, relationships of pALS) decides on opportunities of care pALS is left by his wife after diagnosis and has not any related or family caregiver Non-familial care is voluntary; family care is a duty Social network is very important but not the same as family Family enables pALS to stay at home Having a second job complicates time management Not going alone to physicians because they do not listen to one person only

TABLE 2 (Continued)

Category	Focused codes (examples)	Initial codes (examples)	Theoretical memos on focused codes (examples)
Keeping up with ALS	<ul style="list-style-type: none"> • Having PEG to keep the weight • pALS makes advance planning decisions • Having crisis events • Feeling guilty • Setting up devices for communication • Not being able to provide for a death at home • Ending life with EXIT • Going to hospice • Giving medication 	<ul style="list-style-type: none"> • The course of ALS is unclear • Recommending being honest about the course of the disease • Needing support as the disease progresses • Taking your living will with you • Living wills at ALS are easy to write • pALS plans ahead • Wanting to make an advance directive against the request of pALS • Instruct pALS to make advance directives • Make living wills independently • pALS does not want any life-prolonging measures • Make living wills with case management (parahelp) 	<ul style="list-style-type: none"> • The disease progress of ALS is uncertain and opaque for everyone involved; for people with ALS and informal caregivers as well physicians • With the progression of the disease informal caregivers become overwhelmed due to its often rapid progression • Sorting last things, saying goodbye • Having to hold on to life; being allowed to die • Having a good disease course without affective and cognitive impairments of pALS • pALS wants to be reanimated for the children • Assistive devices and mobility ameliorate social isolation • pALS fears non-invasive ventilation mask and to be at its mercy; cannot take off the mask. Informal caregivers need to be present • Informal caregivers become more professional during the caregiving
Managing everyday life	<ul style="list-style-type: none"> • Being burdened by administrative tasks • Rebuilding the home 	<ul style="list-style-type: none"> • Financial support is important • Impossible to get support with administrative tasks • Not knowing laws well • Support with administrative tasks • Uncertainty with administrative support • Changing the home • Having a lift • Needing help with cooking • Financing home build 	<ul style="list-style-type: none"> • Refitting the house collides with aesthetic preferences; the life after the pALS has died is important as well • Invalidity insurance covers more assistive technology as people are of working age • Installing the lift but pALS died before so not needed • Trying to maintain stability within the family, keeping children's rooms the same way

In Figure 1, the core category is connected to the four secondary categories that are interconnected with each other. In our theoretical understanding, this represents the top-down organising function of the core category as a basic social process in the other categories.

2.1 | Holding the balance

Generally, from the diagnosis of ALS informal caregivers worried about the balance in their lives to care for pwALS. Holding the balance was the core category encompassing all the other categories of work that informal caregivers performed such as balancing family life and caregiving (Table 3, Quote 1). Another participant noted the need to not only balancing family obligations but also keeping up one's own strength in caregiving as an effort to maintain the balance (Table 3, Quote 2).

Crucial for the task of holding balance was the relationship with pwALS as well as the distinct personalities of both the carer and the cared-for. Using the metaphor of a power bank, one caregiver remarked how she was able to go through the caregiving process despite it being tough (Table 3, Quote 3). Whilst the relationship was a source of support, it could also lead to problems in the caregiving trajectory thereby negatively impacting the balance (Table 3, Quote 4).

Also, the balance was majorly impacted by person-related and relationship-related changes due to the disease. Neurocognitive and affective changes did pre-occupy the caregivers, even though the former were more intricate than the latter (Table 3, Quote 5). These behavioural changes and conflicts therefore affect not only how the caregivers were able to maintain a balance in the amount of support they can provide but also how they were able to manage everyday life for pwALS and themselves and organise support that did allow them to have some semblance of a normal life as well as respite support.

2.2 | Managing everyday life

Despite the extraordinary situation of dealing with a terminal diagnosis, participants wished to continue everyday life as normally as

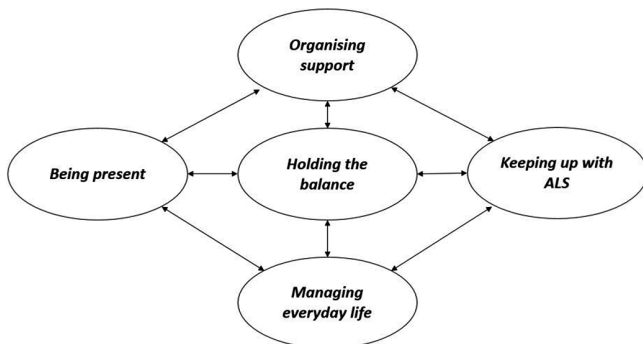


FIGURE 1 Five categories of informal caregiving in amyotrophic lateral sclerosis

possible. However, the terminal diagnosis of ALS impacted life plans and shifted the balance against informal caregivers. As an example, in one case of young-onset ALS, a current caregiver described the decision they faced, as they wanted to start a family (Table 4, Quote 1).

In this example, the normality of family planning was interrupted by the diagnosis of ALS. Informal caregivers generally tried to stick to how their lives were before, consisting of everyday activities providing solace. Generally, family life was reported as being an important aspect of normalcy, next to work life. In the case that informal caregivers had other dependents to care for besides the pwALS, this additionally became a source of burden; however, caregivers reported getting support through their families. For informal caregivers in employment or self-employment, work-life was a major part of this balancing act (Table 4, Quote 2).

To enable the access of support structures, informal caregivers organised personal finances and received welfare support through health insurance and other social insurances which demanded administrative work. The situation of ALS and its progression made these normally mundane everyday tasks complicated and dealing with administration entailed uncertainty and helplessness. Furthermore, different conditions to receive institutional support had an immense effect on the caregivers' ability to carry out caregiving (Table 4, Quote 3).

Another aspect of upholding normalcy was keeping up leisure activities. Listening to music, singing in the choir, living a religious life, spending time with their dog were various activities informal caregivers undertake to balance out their lives.

2.3 | Organising support

In addition to holding the balance and maintaining normality in their lives, informal caregivers were concerned with organising support for pwALS to enable informal caregiving at home for the longest time possible. This support entailed managing visits by friends or seeking social integration of pwALS. The informal support from other friends and family ranged from the assistance of daily living, for example cooking and preparing meals, to hands-on nursing care. Getting or organising informal social support and building networks were key activities of informal caregivers; these were helped if there were already existing peer groups (Table 5, Quote 1).

Additionally, there were various sources of formal support that had to be arranged as well. This included, as for example assistant caregivers, support and advice from experienced nurses specialised in ALS and formal support through ALS centres. Informal caregivers needed and valued experienced and competent care personal. Generally, caregivers remarked needing a large multidisciplinary team to make care feasible at home, constituting several professionals, sometimes privately paid. Ideally, this team would have continuously provided support through the disease course to bereavement. Generally, caregivers appreciated if support was organised for them instead of having to organize it for themselves (Table 5, Quote 1).

TABLE 3 Holding the balance quotes

Quote 1	Current female spousal caregiver, 6009	Well, I have this always in sight and well it is difficult: to find the balance between my son and my husband, the rest of the family and also myself.
Quote 2	Current male spousal caregiver, 7777	We are well prepared. My family physician is the same as my wife's, but she/she supports the whole family. And she says that I need to take care of myself, that I keep my strength and notice/like in sports when you need extra support. It is a balancing act, well, that's what one notices.
Quote 3	Current female spousal caregiver, 9059	What actually helps me is the positive nature of the sick person. That's my power bank (laughs), that's the way it is.
Quote 4	Current female filial caregiver, 5450	But this way/always this fighting/or the voice computer/she had not consented to a voice computer/but then she gets so angry if you don't understand her, but she says 'no' to the voice computer. And that/it's always these fights that we had with each other. But I already understand. It's just a little bit my mother. She just doesn't accept things. She has never/would rather bury her head in the sand and hope that it will pass.
Quote 5	Former female spousal caregiver, 6697	He has laughed crookedly at the beginning at stupid jokes, it is part of the disease, 'sorry', he now said, 'but it is also part of the disease' and of course he cried too, tears came much faster. Then the last time it saw the Christmas tree or that or at all, the illness with a thousand farewells, it really is like that.

TABLE 4 Managing everyday life quotes

Quote 1	Current female spousal caregiver, 0493	Then the diagnosis came and then we discussed how should it go on. And then we decided we would do a few months unpaid and go traveling and then soon afterwards the wedding, or we also went on a long honeymoon. And a child was still in question: yes/no, a child? We waited the first year to see what the course of the disease would look like. And it has a slow progression, so we figured ok let's try it.
Quote 2	Former female filial caregiver, Interview-ID: 6217	At one point you just noticed that it wasn't/that it was no longer possible with full-time work and that's why I actually planned/wanted to take a break ... And that actually went very well/thank God. But with my sister, for example, things looked very different now. She had a lot of trouble being absent from work to keep the appointments and we used all vacation days.
Quote 3	Former female filial caregiver, 8807	I felt completely helpless. I submitted the application for the wheelchair to the old age insurance and then they wanted 7000 things from me, and I work in the administration area in the office, so it's not like that I'm completely unaware of paperwork, but I didn't understand the letters they wrote to me, so really, really bad.

Accessing psychological and spiritual supports played a minor in our sample; however, where they were accessed, the care was important in enabling informal caregivers to deal with difficult feelings and continue providing caregiving as a balancing act.

Searching for information to care for the pwALS was a crucial task for informal caregivers. Here, formal caregivers' knowledge and ability to provide relevant information as well as the ability of informal caregivers to gather information from other sources were crucial

to adapt their care. Another raised issue was the relocation of the pwALS to a nursing home. If informal caregiving was not able to be done at home, or not wished for, pwALS located to nursing home (Table 5, Quote 3).

Here, problems were encountered in nursing homes such as that the care provided was not adequate for pwALS or communication problems arose. Hence, relocation to the nursing homes did not necessarily provide relief for caregivers.

2.4 | Being present

One key activity described by the participants was taking care of the pwALS in such a way that he or she did not feel alone and was not alone in any way that it would endanger him or her. Hence, family caregivers were constantly planning to ensure that they or someone else were present with the pwALS. As long as the pwALS could have stayed at home on their own, it would have been easier for the caregiver to keep the balance as they had to organise less respite support and ensure some level of normal life for the pwALS.

In the caregiving trajectory, time was needed to attend to the pwALS increases with disease progression. It can become round the clock care and attention with increasing debilitation depending on how much the caregiver takes responsibility for caregiving tasks or whether tasks are delegated to healthcare professionals. Therefore, the extent of being present depended on the availability of respite care (Table 6, Quote 1).

Informal caregivers report that if accidents had happened, for example a pwALS had a fall, this increased their vigilance and anxiety. This led some to hire round the clock help, co-habiting with the pwALS, and having to renegotiate privacy as professional caregivers moved in. The need to be available did not stop when the person cared-for enters the nursing home, as a daughter caregiver laid out (Table 6, Quote 2).

2.5 | Keeping up with ALS

The progression of ALS was crucial for caregiving. A quick disease progression was seen as extremely burdening, however, caregivers' understanding of quick differed. Informal caregivers always felt that

they lagged behind in caring for the impairments of ALS, such as dealing with urinary problems, keeping the body weight stable, for example by inserting a feeding tube.

Depending on the progression, pwALS and caregivers made plans for advance care, treatment and end-of-life decisions as well as everyday and bereavement-related tasks. In one interview, where the pwALS was present, it was revealed that whilst the husband had planned for his own funeral, they were yet to decide on the place of death (Table 7, Quote 1).

Other plans centred around handling prognosis and managing expectations. Informal caregivers managed crisis events and difficult feelings like guilt for not being able to do enough. With the progression of ALS towards the latter disease stages, there was an increase in caregiver activity as they tried to keep the pwALS mobile and involved in social life. Together with being present to the pwALS, this kept them connected to the pwALS but at the same time, limited their social life and support. Thus, the end-of-life phase was characterised by shifting the balance of burden towards the family caregiver. Choosing the hospital with a palliative care station as a place of death was a relief for informal caregivers, and they valued hospitals providing such services (Table 7, Quote 2).

The final phase of life of the pwALS was a critical time for family caregivers. At the end of life, coping and acceptance of ALS by the pwALS was crucial for caregivers trying to hold the balance in caregiving. Many problems arose if they do not (Table 7, Quote 3).

If the pwALS did not accept the terminal diagnosis of ALS, this could lead to conflicts with the informal caregiver and with the professionals. Furthermore, if they lost the capacity to make decisions due to dementia or inability to communicate, family caregivers found themselves in moral dilemmas and conflicts with other family members. Hence, staying in communication with the pwALS was a significant

TABLE 5 Organising support quotes

Quote 1	Former female spousal caregiver, 6697	Every Tuesday when we were at the (rehabilitation centre) we met (name of other ALS patient and caregiver), who still, he still has it, for 12 years. He was accompanied by his wife (...) Then she said let us meet half an hour earlier, than we can talk a little bit.
Quote 2	Former female filial caregiver, 8807	Well, yes, from our situation it would have been best if the neurologist who made the diagnosis would have given my address to the care team and they had contacted me.
Quote 3	Former female filial caregiver, 5450	I couldn't sleep anymore, it was just too much of a burden for myself. Spitex came, but it just happened anyway/the responsibility was mine. I was always afraid that I would let her fall or/and then/so she said from the beginning that she was going to the nursing home, that's why it was never the question/ rather 'when?'. But that she would go, we did from the start/yes, so I would have liked her to have stayed with us, but I would have/I couldn't do it on my own. And only with Spitex, I wouldn't have made it. That was the problem.

TABLE 6 Being present quotes

Quote 1	Current female spousal caregiver interviewed with her husband, 4739	So/I'm sometimes tempted to say that I could do this (snaps fingers) and someone is standing here. On Mondays she [pwALS] usually goes to therapy in [city in German-speaking Switzerland], to the hospital/that is the hospital at/near the train station. Actually, the same woman always comes to go there with her. If she doesn't, I'll go, or/or someone else could come [...] Her sister comes here so that she is not alone.
Quote 2	Current female filial caregiver, 3847	And that would/would actually already address the care in the [nursing home], but somehow we also want to give her the feeling that we are there and/she is actually not alone on any evening and we don't want that either she that is.

issue. Together with the pwALS, caregivers accessed several technologies to enable communication at the end of life; however, even the most advanced technologies had problems (Table 7, Quote 4).

Not only communication technology but also ventilation masks and other devices were important from the perspective of informal caregivers during the final stages (Table 7, Quote 5). Also, support and counselling from palliative care professionals on how to handle end-of-life situations at home needed to be head on (Table 7, Quote 6).

There were informal caregivers who reported not being able to support the pwALS at home for the final phase with the need to relocate the pwALS to a care home or a hospital. However, it was clear that most caregivers really pondered the question of how to provide care until death for the pwALS (Table 7, Quote 7).

The responsibilities of organising and administering medication at home fell onto the caregivers and their networks. Specialist's advice and care were needed to feel prepared to provide end-of-life care, even though some caregivers also pointed out that complete preparation was never possible. Especially the administration of morphine on part of the informal caregiver was a difficult activity. To enable the pwALS to die at home therefore meant becoming more specialised in caregiving and providing palliative care in the home care setting (Table 7, quote 8).

At home, one important mediator for informal caregivers was the availability of respite and day support with the progression of ALS. In a few cases, informal caregivers also used hospice care as a form of respite support. Generally, caregivers appreciated hospices as places where death was not taboo (Table 7, Quote 9).

After the death of the pwALS, not only bereavement and administrative-related tasks were carried out by informal caregivers but also searching for and accessing help with difficult feelings of grief, if needed.

3 | DISCUSSION

Our theoretical understanding underlined five categories. The core category, holding the balance in ensuring care and normalcy as the disease progresses and until the end of life, is the basic social process of caregiving for pwALS and therefore guides decisions surrounding caregiving. On this understanding, those caregivers who succeed in holding the balance are able to provide care at home until death. Holding the balance is heavily influenced by contextual factors of caregiving, for example relating to personal characteristics of the caregiver (abilities to *hold the balance, manage everyday life*) or activities of caregiving

(*being present, organising support, keeping up with ALS*), where the goal is to ensure the quality of life of the pwALS. As this theoretical understanding is independent of heterogeneity and speed of progression of ALS, our work accounts for multiple caregiving trajectories – those closer to the slow progression of chronic neurodegenerative illnesses and cancer (Murray et al., 2005) and those closer to the unexpected death trajectory in acute brain injury (Creutzfeldt et al., 2015).

In other neurodegenerative diseases, accounts of informal caregiving have highlighted similar caregiving processes. For children with neurodegenerative diseases, Steele (2000) wrote about the process of *navigating uncharted territory*, where she discusses how families of children with neurodegenerative illnesses are aiming at *living on a plateau*. She further states that whilst 'families worked hard to extend the length of the plateaus' (Steele, 2000, p. 58), these plateaus are disrupted by crisis events and interventions characterising progressive neurodegenerative diseases. Similarly, Penrod et al. (2011) describe informal caregiving in their model of expected, mixed or unexpected end-of-life trajectories as phases of *Sensing a Disruption, Challenging Normal, Building a New Normal* and *Reinventing a Normal*. In the context of the expected death trajectory such as ALS, reinventing a normal is replaced by *Losing a Normal* (Penrod et al., 2011). These phases help those experiencing the situation to make sense of adaption to ALS but are too unspecific. Whilst our understanding of caregiving is compatible with 'phases [that] are demarcated by key transitions experienced when the illness progression manifestly challenges the established steady state achieved by the caregiver' (Penrod et al., 2012, p. 174), in ALS this progression is foreseeable. Hence, the work informal caregivers do is not only reactive (achieving the steady state after crisis) but also anticipative (upholding the steady state). The basic process of holding a balance as outlined in our study is not directly connected to an understanding of normality. This is because we do not want to ascribe normality to the difficult process of holding the balance, even though rendering this into terms of 'new normal' might be fitting. However, we emphasise upholding normality in our model in the category of managing everyday life. This fits well onto the theme of *just getting on with it* in a study with informal caregivers of pwALS in Ireland, the United Kingdom and the Netherlands (Conroy et al., 2021). Nonetheless, managing everyday life is also a source of burden and work. Generally, studies in Ireland, the United Kingdom and the Netherlands (Conroy et al., 2021), the United States (Brizzi et al., 2020) and Germany (Schischlevskij et al., 2021) underscore in line with our study both the practical and the anticipative character of supportive care for pwALS and their family caregivers.

Quote 1	Female spousal caregiver, 6009	Aha, um I talked to my husband. I don't know if he did something, but yes, we want to do that/we would do that/we would do that. Um, we discussed whether he would stay at home or go to the hospital or somewhere. Um but that's not yet/not yet decided.
Quote 2	Former female filial caregiver, 6217	Yes, they were really amazing, they were really very good. My mother felt very comfortable just in the hospital we had every now and then/just/we/we had to go over at night because she was a bit panic – which has nothing to do with the nurses, but it was just the situation/she was better off in this palliative department because they knew better how, where, what.
Quote 3	Current female friend caregiver, 8694	Nevertheless, they could not offer this care in the way he wanted them to. He needs everything because he wants to get well again. Therefore, we had this discussion again this morning. He still does not see himself as a palliative patient, despite this extreme progression.
Quote 4	Former female filial caregiver, 6217	You also noticed because my mother couldn't speak anymore and things didn't always go well with this computer, they really came into the room and have already read through everything and said: 'I've read this and that' and then my mother just had to blink. We explained it a bit like this and that and that actually works a lot through the eyes we also made a board with the most important things that you can ask if it is that could be.
Quote 5	Former female spousal caregiver, 0735.	But it worked, from there on we had to have an oxygen device, first at night, afterwards we had to have the oxygen device with the bottle and the backpack.
Quote 6	Current female spousal caregiver, 4739	I found that actually/just good/you are talking about the same thing/there is plain text, so there is no beating around the bush.
Quote 7	Former male spousal caregiver, 1139.	Or how do you enable the family to look after someone at home in a good way? That is the reverse question for me/for a nursing home or an acute hospital one could have gone at any time. So you could have said at any time: call an ambulance and move [name of patient] to the hospital, but that wasn't the idea. We all wanted that, that she can be at home here. But how to set up the network at home for this care?
Quote 8	Former female spousal caregiver, 3719	And then there is no rest either, I then injected morphine regularly, every 2–3 hr for weeks. And that was, yes, very stressful.
Quote 9	Former female spousal caregiver, 6697.	It was also a happy house, there was no deathly silence in there now, not at all, you kept hearing people laughing.

TABLE 7 Keeping up with Amyotrophic lateral sclerosis quotes

Much of the support provision is mediated by the caregiving relationship. Bassola et al. (2020) used a grounded theory to shed light on interpersonal processes involved in the caregiving dyad in ALS. Their analysis yielded three main categories 'reciprocity', 'loving to care' and 'changing to care' and four secondary categories: 'having support', 'sharing suffering', 'protecting each other' and 'thinking positive' (p. 3). Whilst interpersonal processes were not the focus of our analysis, these categories outlined here map onto our findings that caregiving depends on intra- and interpersonal processes (e.g. acceptance of diagnosis on part of pwALS).

Our theoretical understanding is adaptable in explaining caregiving and decisions of informal caregivers and their families. It can be adapted to understand slowly progressing courses of disease (with very few crisis events and much time for caregivers to achieve a steady state) as well as to highly volatile caregiving courses. It underlines the importance of stressors (bringing the caregiver and family system out of balance) and resources (activities that help the caregiver) that shift the balance in favour or against informal caregivers. This flexibility is needed for any theory of informal caregiving in ALS, as disease progression, personal

characteristics, welfare state support and dynamics within the family systems differ in every case. Therefore, the theoretical understanding of informal caregiving in ALS has its utility in being adapted to individual cases and as a heuristic to approach informal caregiving in ALS for healthcare providers, family members and others.

The key approach resulting from our theoretical questions is resource oriented but also looks at needs for support in individual cases, what exactly might help informal caregivers to hold the balance. This is complementing current policy and practice which is deficit oriented. For example, the Carers' Alert Thermometer (O'Brien et al., 2019) assesses the current situation and needs of informal caregivers, however, as outlined by our theoretical understanding it could be added with a prospective perspective. Whilst the progression of disease and of the caregiving course are uncertain, several foreseeable situations are leading to shift the balance against or in favour of the caregiver. Whilst generally, planning in advance has been widely accepted for healthcare situations, similarly, this could be adapted for informal caregivers' needs.

3.1 | Limitations

This theory is only broadly testable because it is circular; if one would find that the balance had shifted negatively, necessarily the caregiver would experience burden or distress. By and large, the main limitation of this grounded theory study is that it did not employ theoretical sampling in the recruitment of participants. The development of the theoretical understanding therefore is limited by the characteristics of the participants taking part in our study. Furthermore, our sample is not representative of informal caregivers of pwALS in Switzerland.

4 | CONCLUSION

This study suggests that in a constant endeavour to hold the balance, informal caregivers for pwALS provide care and make decisions. This theoretical understanding helps if informal caregivers lose their balance in the tightrope-walk of providing care to a dying person and interventions and support by healthcare professionals can be directed to shift the balance in favour of the caregivers. Our theoretical understanding primarily adds to the existing literature on caregiving processes in ALS. Together with these other studies, it can be used to paint a rich picture of informal caregiving in ALS, especially during the later caregiving stages.

ACKNOWLEDGEMENTS

We want to thank all the informal caregivers who participated in this study. We are also indebted to Prof. Dr Tanja Krones, Prof. Dr Bernice Elger, Dr Kathi Schweikert and Luzia Iseli for their support of the overall project. Open Access Funding provided by Universitat Basel.

ETHICS APPROVAL

The project was submitted for review by the cantonal research ethics committee (Ethikkommission Nordwest- und Zentralschweiz, EKNZ) through swissethics. As the project does not qualify as research with human subjects under Swiss laws, a certificate of non-objection was issued by the EKNZ. Despite not being subject to human research laws, we felt that it was necessary to uphold the standards required by the same laws of Switzerland, that is having written informed consent of every participant, as well as storing data separately in a de-identified manner. Furthermore, no identifying information is presented in the paper that could jeopardise confidentiality.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on reasonable request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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How to cite this article: Poppe, C., Verwey, M., & Wangmo, T. (2022). "Walking a tightrope": A grounded theory approach to informal caregiving for amyotrophic lateral sclerosis. *Health & Social Care in the Community*, 30, e1935–e1947. <https://doi.org/10.1111/hsc.13625>