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QUALITATIVE PAPER

Self-perceived functioning and (instrumental) activities of daily living questionnaires after a hip fracture: Do they tell the same story?

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Abstract

Background: (Instrumental) activities of daily living ((I)ADL) questionnaires are often used as a measure of functioning for different purposes. Depending on the purpose, a measurement of functioning that includes subjective patient perspectives can be relevant. However, it is unclear to what extent (I)ADL instruments capture self-perceived functioning.

Objective: Explore what functioning means to older persons after a hip fracture and assess the extent to which (I)ADL instruments align with self-perceived functioning.

Design: Qualitative interview study with framework analysis.

Setting: Prospective cohort study on recovery after a hip fracture among older persons in a hospital in a large city in the west of the Netherlands.

Subjects: Eighteen home-dwelling older persons (≥ 70 years) who had a hip fracture 6–12 months ago.

Methods: Telephone interviews about functioning before and after the hip fracture were coded and analysed using the framework method.

Results: The activities mentioned by participants to be part of their self-perceived functioning could be split into activities necessary to maintain the desired level of independence, and more personal activities that were of value to participants. Both the ‘independence activities’ and the ‘valued activities’ mentioned went beyond the activities included in (I)ADL questionnaires. Due to various coping strategies, limitations in activities that are measured in the (I)ADL questionnaires did not necessarily lead to worse self-perceived functioning.

Conclusion: Self-perceived functioning differs from functioning measured with (I)ADL questionnaires in the items included and the weighing of limitations in activities. Thus, (I)ADL instruments alone are not enough to measure functioning from the perspective of the older person.

Keywords: self-perceived functioning, (instrumental) activities of daily living, hip fracture, older people, qualitative research

Key Points

- (Instrumental) activities of daily living ((I)ADL) questionnaires do not measure what older persons consider to be functioning.
- Self-perceived functioning includes a broader scope of activities, such as participation and personally valued activities.
- Coping strategies and pre-fracture functioning play a role in post-fracture self-perceived functioning.
- To measure functioning from the perspective of the older person (I)ADL questionnaires are not enough.

Introduction

Hip fractures are seen as a tipping point in an older person's life. The 1-year mortality is about 25% and, of those surviving, another 20% is permanently institutionalised. Furthermore, they have a major impact on multiple aspects of physical functioning. About half of the surviving patients fail to return to their previous mobility and only 40–70% regain their overall pre-fracture level of activities of daily living (ADL) and instrumental activities of daily living (IADL) within 1 year after the hip fracture [1–3].

Both in research and clinical practice, outcome after a hip fracture is usually expressed in terms of mortality, institutionalisation, mobility and functional status [4]. Functional status, measured with instruments such as the Barthel Index, Katz ADL and Lawton IADL, is measured for different purposes, for example to assess level of recovery or support needed. An inherent part of level of recovery or support needed is a patient's own perspective on his/her functioning. Thus, to be able to measure level of recovery or support needed, (instrumental) activities of daily living ((I)ADL) instruments should align with patient perspectives on their own functioning, which are affected by for example personal factors such as coping styles and environmental factors such as existing support [5–7].

Despite the frequent use of instruments such as the Barthel Index, Katz ADL and the Lawton IADL, it is unclear to what extent these instruments capture patients' own perspective on their functioning [8–10]. Involvement of patients (or older persons in general) in the development or evaluation of these instruments was not reported, and there are no other studies known by the authors that compare these (I)ADL instruments to patients' perspectives on functioning [9, 11–14]. Therefore, the aim of this study was to explore what functioning means to older persons after a hip fracture and to assess the extent to which frequently used (I)ADL instruments align with this self-perceived functioning.

Methods

Study setting and design

This qualitative study was part of the prospective cohort study HIP CARE (Hip fractures: Inventarisation of Prognostic factors and Their Contribution toArds Rehabilitation in older pErsons) (NTR NL7491). In the HIP CARE study, which started in December 2018, patients who were admitted with a hip fracture to the emergency department of the Haaglanden Medical Center, one of the largest teaching hospitals in the west of the Netherlands, were included. Questionnaires and function tests were administered at hospitalisation and at 6 weeks and 3 and 12 months after discharge at regular outpatient visits. The aim of the HIP CARE study was to describe recovery patterns up and till 1 year after a hip fracture [15]. For the qualitative study, patients from the HIP CARE study cohort were invited for semi-structured in-depth interviews to explore patients'

perspectives on the concept and own level of functioning. The interviews were enriched with quantitative data of ADL and IADL questionnaires taken at hospitalisation and at the end of the interview. The HIP CARE study, including the qualitative study described in this paper, was approved by the Medical Ethics Committee Southwest Holland (P18.029).

Participants

Patients were eligible for the HIP CARE study if they met the following criteria: (i) a unilateral proximal femoral fracture, (ii) aged ≥ 70 years, (iii) no pre-fracture nursing home residence, (iv) eligible for geriatric rehabilitation and (v) no pathological fracture. Additional inclusion criteria for the qualitative study were (i) no known dementia or cognitive impairment (6CIT ≤ 11 points) and (ii) between 6 and 12 months after the hip fracture at the time of sampling. At the time of sampling (March 2020), there were 95 patients included in the HIP CARE study, of which 42 were between 6 and 12 months after their hip fracture and alive. Thirty-five of these did not have cognitive impairment and were eligible for this qualitative study. They received an information letter about the study with the invitation to participate. After 1 week, they were contacted by telephone to provide clarifying information and to ask consent for an interview by phone. Reasons for refusal were listed when provided. Participants were recruited using consecutive sampling and recruitment continued until no new insights or ideas came up during the interviews. All included participants gave verbal (recorded) informed consent for the interviews.

Data collection

Data were collected in April and May 2020 by two members of the research team, who had a background in health and life science (I.L.T.), medicine (W.M.R.) and vitality and ageing (I.L.T. and W.M.R.). The research team as a whole had extensive experience in qualitative research and research with older persons. In total, 18 out of 35 invited older persons agreed to participate.

The interviews, with a median duration of 58 minutes (range 26–100 minutes), were conducted in Dutch using a semi-structured topic list containing questions about participants' current functioning, the change in functioning they experienced due to the hip fracture and their interpretation of the term functioning (Appendix 1). Follow-up questions were posed when needed. In everyday life, the terms functioning, independent functioning and daily functioning are used interchangeably to describe the same concept. Although these terms overlap, there are also subtle differences between them. All three terms were included in the questions of the topic list to ensure that participant's views on functioning were fully captured. The topic list was pilot tested by both interviewers (I.L.T. and W.M.R.) and subsequently minor adjustments to the questions were made to make them easier to understand. One of the pilot interviews was valuable enough to include in the data-analysis, the other was excluded because the

participant did not meet the inclusion criteria of this study (i.e. interview was not at 6–12 months after the hip fracture).

At the end of each interview, the Katz ADL (scale 0–6, higher score means more dependence), Lawton IADL (scale 0–12, higher score means more dependence) and Parker Mobility Score (PMS; scale 0–9, higher score means better mobility) questionnaires were conducted and a few questions about participants’ opinion on these questionnaires were asked (Appendix 1) [13, 14, 16]. Participants were given the opportunity to do this last part of the interview (i.e. questionnaires and questions on opinion) at a later moment if they were tired after the first part of the interview. Three participants used this option. Field notes were made directly after the interviews and all interviews were audio recorded, transcribed ad verbatim and de-identified.

Data analysis

Data were analysed using the framework method [17]. Coding and analysis of the interviews started during data collection. Transcripts were read multiple times and coded by two members of the research team (I.L.T. and W.M.R.). To be able to extract information from the interviews without imposing preconceived categories or theoretical perspectives, the first two transcripts were coded by ILT and WMR using open, inductive coding. Emerging codes were discussed and compared within the research team, consensus was reached on the codes, and a structured codebook with the inductively derived codes was made (i.e. 80 codes in 9 categories). I.L.T. used this list of codes to code the other transcripts, and when new codes emerged from the data, they were added to the codebook. Subsequently, the inductively derived codes were rearranged into overarching categories. Based on scientific models and theories on functioning and coping, namely the ICF-model, the SOC-model and a study by Huijg *et al.* on successful ageing, codes and categories were added to make the codebook more comprehensive (i.e. 93 codes in 21 categories) [5, 18, 19]. On completion of data collection, all transcripts were also fully coded by W.M.R. using the categorised and enriched codebook, and consensus on the coding of all transcripts was reached between I.L.T. and W.M.R. Throughout the coding process, the codebook was adjusted when needed and notes on emerging ideas and concepts were taken. The analysis continued by grouping codes within the overarching categories into meaningful clusters. Relations between categories were explored and themes were identified resulting in a conceptual model of self-perceived functioning. Congruence between self-perceived functioning and the results of the (I)ADL questionnaires was assessed by comparing the (I)ADL domains with the related findings in the interviews. Furthermore, throughout the analysis, there seemed to be differences in self-perceived functioning and how this functioning changed after the hip fracture depending on pre-fracture self-perceived functioning. Therefore, we explored what contributed to this difference by using a matrix (i.e. a chart) which enabled us to order mentioned activities and coping strategies grouped by self-perceived

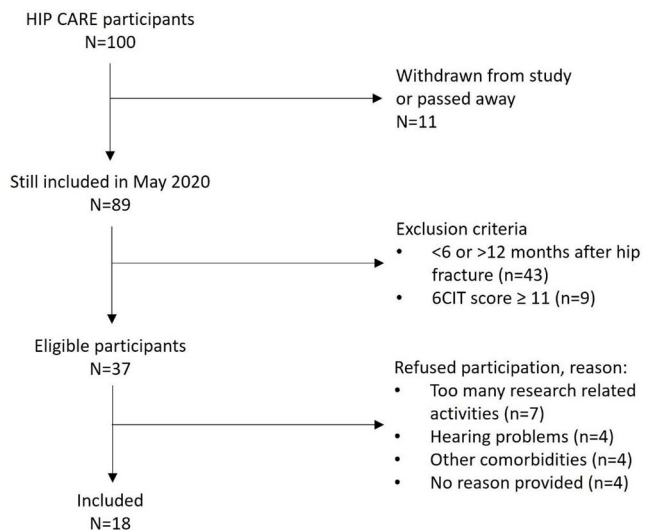


Figure 1. Flowchart

pre-fracture functioning. Atlas.ti version 9, a computer-assisted data analysis programme, was used to code and analyse all the data. Quotations from the interviews included in this paper were translated from Dutch to English by a native English speaker in collaboration with one member of the research team (W.M.R.).

Results

A total of 18 patients were interviewed between 6 and 12 months after their hip fracture (Figure 1). Their median age was 79 years (range 71–95) and 11 (61%) were female (Table 1). At hospitalisation, they reported to have a median Katz ADL of 0 (range 0–3), Lawton IADL of 1.5 (interquartile range (IQR) 0–5) and PMS of 8 (IQR 6.75–9) before their hip fracture. At the time of the interview, participants had a median Katz ADL of 0 (IQR 0–4), Lawton IADL of 3.5 (IQR 1.5–6.25) and PMS of 6 (IQR 5–7.25).

The themes and relations observed in the interviews were summarised in a conceptual model comprising (i) components of self-perceived functioning, (ii) the effect of coping strategies on self-perceived functioning and (iii) the influence of pre-fracture self-perceived functioning on post-fracture self-perceived functioning. The components could be split into two main types: on the one hand, activities necessary to maintain the desired level of independence, such as driving a car; on the other hand, more personal, often participation-related activities that were of value to participants, such as gardening or going out. Both the ‘independence activities’ and the ‘valued activities’ mentioned went beyond the activities included in ADL and IADL questionnaires. Limitations in these did not necessarily lead to worse self-perceived functioning (i.e. second part of the model). Different coping strategies to deal with limitations could be observed. For example, participants who had to use a walker since the hip fracture described their aid as just a useful tool that made life

Table 1. Characteristics of participants

	Included participants
<i>N</i>	18
Female, <i>n</i> (%)	11 (61)
Age at interview, median (range)	79 (71–95)
Months since hip fracture, median (range)	9 (5–12)
Functioning before the hip fracture	
Katz ADL, median (range) ^a	0 (0–3)
Lawton IADL, median (IQR) ^b	1.5 (0–5)
Parker mobility score, median (IQR) ^c	8 (6.75–9)
Functioning at time of interview	
Katz ADL, median (range) ^a	0 (0–4)
Lawton IADL, median (IQR) ^b	3.5 (1.5–6.25)
Parker mobility score, median (IQR) ^c	6 (5–7.25)

^aKatz ADL range 0–6, higher score means more dependence. ^bLawton IADL range 0–12, higher score means more dependence. ^cParker Mobility Score (PMS) range 0–9, higher score means better mobility.

easier but did not change their self-perceived functioning. Finally, self-perceived pre-fracture functioning also seemed to be related to self-perceived post-fracture functioning. Both participants who were still very active before their hip fracture and participants who already had several limitations before the fracture felt more comprised in their functioning because of their limitations than the other participants.

Components of self-perceived functioning

For participants, self-perceived functioning consisted of two types of activities. The first type was activities needed to maintain the desired level of independence, as shown by the often used generic reply ‘being able to do everything myself. Which specific activities participants had in mind with ‘everything’ differed, but for all of them these activities included not only ADL and IADL items, but also other, more advanced, activities. More advanced or heavier (household) activities that came up were for example managing administrative tasks or window cleaning.

‘Well yeah [my independent functioning has changed], you are of course a bit limited with some things. Like I just mentioned, vacuuming, and you know, cleaning the shower and the toilet. Yes, and cleaning the windows of course. You sometimes have to do a little extra. So, uh I did that of course before, of course I did. I just can’t do it anymore, I sometimes just can’t.’ (P3)

In many of these independence activities, mobility played an important role. Participants for example said it was necessary to be able to walk outside or drive a car in order to be able to do the grocery shopping. In these cases, mobility was often more a means to an end. Participants facing limitations in mobility said these limitations hindered them in their independent functioning.

‘Yes I mean I can write a letter, but I can’t post that letter because I can’t get to the post box. (...) Well, independent functioning doesn’t really happen’ (P11)

The second type of activities that were part of self-perceived functioning was more personal, ‘valued’ activities [20, 21]. Many of these valued activities had to do with participation, for example going out, (voluntary) work and visiting friends and family, but also included activities such as gardening or reading a book. An important aspect of the valued activities was that they either gave participants a sense of fulfilment, or they were an enjoyable pastime for participants.

‘Yes, that is, the work also involves social contacts, of course. With the wholesaler or so you would have a chat, you would have a chat with the client and uh. Yeah uh that just still gave satisfaction, that uh that work, and that uh you’d miss that.’ (P18)

Again, mobility played an important role, but in this case more as an end in itself rather than a means to an end. Activities such as biking or driving a car gave participants a feeling of freedom and allowed them to do whatever and go wherever they wanted. A participant who could not bike anymore described it as follows:

‘I’m an outdoors person, I want to go into nature, I uh I’d cycle to Schiphol to look at the aeroplanes. I, I, I know all of South Holland. Uh and I miss it a lot.’ (P1)

The effect of coping strategies on self-perceived functioning

Almost all participants described some loss of function in the above-mentioned activities after their hip fracture. Most of these losses hindered participants. Where possible they compensated their losses by using aids or help from formal and informal caregivers. These aids and help were considered to be a necessary evil by most, but not something that affected their functioning. A few were more positive about their aid, describing it as something they did not want to use at first but over time they came to consider their aids as just a useful tool that made their life easier. However, a few participants noted that the strain their limitations put on their informal caregivers did play a role in their own evaluation of functioning. They thought this aspect was insufficiently included in the ADL and IADL questionnaire.

In addition, some participants also changed the way they performed activities, for example cleaning the house a bit less thoroughly or using furniture to move through the house. Despite these limitations and necessary adjustments, overall self-perceived functioning was said to be good by most or even unaffected by some. However, when losses led to a complete inability to do an activity, this had more influence on self-perceived functioning.

‘I can just do my own thing. I can walk to the shed. I can walk outside. And that’s no problem. I can walk the dog. Well yeah, with the walker but yeah. But I can still take him out and I make long walks. That’s why I use my walker, because I also go for long walks of at least four kilometres and I enjoy that.’ (P2)

'And then I do the dusting and check whether things are dirty, check whether I feel I should clean something. And then, well uh, I do, I do it my way. I used to do it differently, better probably, but I don't know, it's also good in this way.' (P7)

'Well, honestly I'd like that (cycling) a lot, but I don't dare to do it. Because I know that my, that my leg with the broken hip, my left leg, isn't stable enough if I have to get off the bicycle, suddenly. Then I don't trust myself. And yes you want to especially avoid that it happens again of course. And personally, I find it a big, a really big limitation.' (P12)

Participants also described accommodative strategies to deal with their limitations and adjustments. For example, some said their limitations were part of the process of getting older and thus not something that said anything about their level of functioning. Comparison with others who were worse off or with a hypothetical worse scenario was also used to minimise the importance of the own limitations. Furthermore, participants justified their disabilities by framing it as their own choice of not doing something anymore. All of these assimilative and accommodative strategies were used to accept the current situation and to unlink limitations from the overall evaluation of their own functioning.

'I have no limitations. (...) That I'm not cycling anymore, well yes that is my own choice. Because I am cautious.' (P2)

Influence of self-perceived pre-fracture level of functioning

However, there were two groups of participants who felt more compromised in their functioning because of their limitations. The first group included participants who were still very active before the fracture, for example those who still had a paid job, and therefore were prone to lose a lot of their usual, and often valued, daily activities due to the hip fracture. They felt severely compromised in their functioning. Some of them felt they were all of a sudden confronted with getting older and losing function because of that, which came with more negative feelings and judgements of the current situation. At the same time, they did not recognise themselves in their (often unchanged) questionnaire score and thought the items in the questionnaire did not cover their true functioning.

'But when I get these questions I think yes ... I feel that actually I can do quite a lot still if I can answer all these questions with dependent uh or independent, than I think well, it isn't that bad, but let me say it doesn't feel like that.' (P18)

The second group included participants who already had limitations in (more basic) ADL and IADL activities before the fracture. They felt that the new, additional limitations resulting from the hip fracture took away even more of their independence. Their questionnaire score changed similarly to that of other participants, but these participants felt they could not compensate for their additional limitations anymore.

Discussion

Functioning of patients after a hip fracture is often measured with (I)ADL questionnaires in research and clinic. However, this study shows that what is measured with (I)ADL questionnaires is different from functioning as perceived by the older patients themselves. Firstly, for the older patient a broader scope of activities is part of self-perceived functioning than what is included in (I)ADL questionnaires. Besides (I)ADL activities, self-perceived functioning included more advanced activities needed to maintain independence, activities related to participation and other valued activities that gave a sense of fulfilment. Second, the effect of a limitation on self-perceived functioning differed between activities, while limitations are weighed equally in (I)ADL questionnaires. Limitations that could be compensated for and those that were considered to be normal in the current situation or age hardly changed self-perceived functioning in the current study. On the other hand, limitations that led to a large change in functioning or to a high level of dependence had a large effect on self-perceived functioning. In other words, different coping strategies and pre-fracture abilities and inabilities played an important role in post-fracture self-perceived functioning, something that is not taken into account in (I)ADL questionnaires.

There are many different types of instruments that aim to measure functioning. They differ from each other in what they exactly measure, in particular the items included and how much room they leave for subjective interpretation [7]. Previous research on assessment of recovery and on successful ageing already described a broader scope of activities being relevant to patients themselves [5, 20, 21]. In these studies mobility, valued day-to-day activities, activities related to independence, social contacts and engagement with life were reported by older persons to be important. The findings in the current study show that the same components play a role in self-perceived functioning. These components cover both the 'activities' and the 'participation' of the ICF model [18]. Contrary, (I)ADL questionnaires, or instruments such as the PROMIS physical functioning questionnaire which include a broader scope of activities, only cover some of the 'activities' of the ICF model, while other instruments are used to measure participation, for example the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-P) [22, 23]. Thus, what older persons consider to be functioning is measured with multiple instruments in research and clinic.

Concerning the room for subjective interpretation, Griffiths *et al.* (2015) already observed the influence of pre-fracture functioning and the ability to make adaptations on the perceived level of recovery, something also described in research on the disability paradox [20, 24]. Viret *et al.* (2019) further explored this relationship by looking at the relation between autonomy and functional decline. They described a difference in what autonomy consists of depending on the current amount of limitations. For those with less limitations autonomy is 'to do what I want', while for those with more limitations autonomy is 'to do what I can'. Autonomy was

always expressed as relative to others or to previous autonomy. In other words, limitations are not weighed equally by patients themselves (i.e. because of recalibration, reprioritisation or reconceptualization), something also observed in the current study [7]. Many instruments that are currently used to measure functioning (i.e. activities or participation) do not leave room for interpretation in the rating. Concerning both the activities measured and the weighing of limitations, Huijg *et al.* (2017) concluded that solely applying objective criteria results in a mismatch between how successful older individuals feel and how successful they are classified by these objective criteria. They state that a mix of objective and subjective measures is needed to measure the patient perspective on successful ageing [5]. In the current study, the same mismatch was observed for the concept of self-perceived functioning, both in what is actually measured, the items included and the weighing of limitations.

Strengths and limitations

As far as the authors are aware of, this is the first study to combine both quantitative questionnaire data and qualitative interview data on functioning. This allowed a comparison between the two and thus a better exploration of what is relevant for patients and how this differs from the objective criteria of (I)ADL questionnaires. In particular, the reflections of patients on the questionnaire directly after administering them were very helpful on this point. Another strength of this study is the chosen time frame within the recovery process (i.e. 6–12 months after hip fracture). Most of the recovery after a hip fracture is expected within these first 6 months. Thus, the participants of this study were at the end of their recovery process and had a clear idea of what was relevant for their functioning. An important limitation of this study is the over-the-phone instead of real-life interviewing. In an over-the-phone interview non-verbal cues are less prominent. Without these cues, it is hard to interpret the meaning of a response, to evaluate whether the response is valid and to judge the emotional state of the respondent. Despite these missing non-verbal cues, the interviews provided relevant new information on self-perceived functioning. Another limitation of this study is related to its position as a sub study in a larger study on recovery after a hip fracture. As a result, participants were frequently contacted for study purposes and some felt overloaded by it. This might have resulted in the low inclusion rate in the study currently reported. Furthermore, participants who were included in the current study sometimes felt the same things had been asked in previous contacts and therefore might have been less elaborate in their responses.

Conclusion

To conclude, self-perceived functioning is different from functioning as measured with (I)ADL instruments. Firstly, they differ in the items included, as self-perceived functioning includes more advanced and more personal

valued activities, such as participation activities, besides the (I)ADL activities. Secondly, contrary to how limitations are weighed in (I)ADL instruments, the weighing of limitations in self-perceived functioning is influenced by pre-fracture status and different coping strategies applied. When using an (I)ADL instrument, researchers and clinicians should be aware of these limitations of the instruments. Although (I)ADL questionnaires can be useful to measure functional status according to a fixed set of objective criteria, they do not include patient perspectives on functioning and are therefore not fit for every purpose they are currently used for. In research, where objectivity and inter-person comparability of an instrument is important, measuring participation and a broader scope of activities with more extensive instruments or with additional instruments can bring the measurement of functioning closer to self-perceived functioning. However, when patient perspectives are important, for example in clinical practice when assessing level of recovery or support needed, it is better to engage directly with patient view and experience rather than using (extensive) (I)ADL instruments.

Supplementary Data: Supplementary data mentioned in the text are available to subscribers in *Age and Ageing* online.

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Declaration of Conflicts of Interest: None.

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Data Sharing Statement: Request for access to the data are to be addressed to the corresponding author.

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