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Using brain-computer interfaces: a scoping review of studies employing social research methods

Johannes Kögel[*], Jennifer R. Schmid, Ralf J. Jox and Orsolya Friedrich

Abstract

Background: The rapid expansion of research on Brain-Computer Interfaces (BCIs) is not only due to the promising solutions offered for persons with physical impairments. There is also a heightened need for understanding BCIs due to the challenges regarding ethics presented by new technology, especially in its impact on the relationship between man and machine. Here we endeavor to present a scoping review of current studies in the field to gain insight into the complexity of BCI use. By examining studies related to BCIs that employ social research methods, we seek to demonstrate the multitude of approaches and concerns from various angles in considering the social and human impact of BCI technology.

Methods: For this scoping review of research on BCIs' social and ethical implications, we systematically analyzed six databases, encompassing the fields of medicine, psychology, and the social sciences, in order to identify empirical studies on BCIs. The search yielded 73 publications that employ quantitative, qualitative, or mixed methods.

Results: Of the 73 publications, 71 studies address the user perspective. Some studies extend to consideration of other BCI stakeholders such as medical technology experts, caregivers, or health care professionals. The majority of the studies employ quantitative methods. Recurring themes across the studies examined were general user opinion towards BCI, central technical or social issues reported, requests/demands made by users of the technology, the potential/future of BCIs, and ethical aspects of BCIs.

Conclusions: Our findings indicate that while technical aspects of BCIs such as usability or feasibility are being studied extensively, comparatively little in-depth research has been done on the self-image and self-experience of the BCI user. In general there is also a lack of focus or examination of the caregiver's perspective.

Keywords: Brain-computer interfaces, Neuroethics, Empirical research, Quantitative methods, Qualitative methods, User experience

Background

Research on Brain-Computer Interfaces (BCIs) has seen a rapid development in the last 10 years [1]. A BCI is defined as a device that measures activity of the brain or central nervous system and converts these signals into artificial output [2]. BCIs thus detect and process brain and nervous system activity in order to control and direct external devices, such as personal computers, robotic arms, wheelchairs, or to activate a person's own muscles [3–8]. A large area of application is in the use of BCIs in combination with medical devices, in order to increase communication or motor control for persons with physical impairments. BCIs have also been implemented in neuro-rehabilitation to improve neurological conditions such as motor paralysis after stroke or spinal cord injury [9, 10], as well as epilepsy [11]. Research has demonstrated that there are many uses for BCIs, including medical uses such as the treatment of psychiatric conditions, as well as non-medical uses such as neuroenhancement or in gaming products [12–14].

Relevant brain activity from BCI users can be detected either with non-invasive (mostly with electroencephalography (EEG)) or invasive methods [6, 9, 15–17]. Three

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* Correspondence: johannes.koegel@med.uni-muenchen.de
Institute of Ethics, History and Theory of Medicine, LMU Munich, Lessingstr. 2, D-80336 Munich, Germany

types of brain activity production and use by the technology can be distinguished [18]. (1) *Passive BCIs* use brain activity not voluntarily produced by the person, such as mental workload or affective states [18]. (2) *Reactive BCIs* are based on changes in brain activity which occur as a result of an individual's voluntarily focused attention on a specific external stimulus (mostly visual, but also auditory or somatosensory) among a multitude of irrelevant stimuli [5, 18]. (3) *Active BCIs* require that the user applies a certain mental strategy (e.g. imagining moving a limb) [5, 18]. In virtually all BCI types, users receive real-time feedback on their brain activity output, through visual (most common), auditory, tactile, vestibular, or proprioceptive feedback [5]. Certain closed-loop applications of BCIs also apply stimulation to the brain by using electrodes which have been implanted in the brain, for instance in the treatment of epilepsy, or psychiatric disorders [19].

To understand BCI beyond its technical components and medical applications, significant social research is needed to grasp BCI in its practical and human dimension. Insights into the use of BCI and its impact on the user are necessary to develop the relevant knowledge and tools for ethical and legal evaluation.

The manner in which subjectivity or identity is molded by technology is an important issue for many different human-machine interactions, but especially in BCI applications (e.g. [20–22]). Entirely new characteristics involved in BCI, for instance incorporated technologies such as implants, or self-reliant and environment co-creating technologies, have the potential to influence the future of human-machine interaction. BCIs often employ these breaking threshold technologies and therefore present a crucial area of research in the molding of subjectivity through mediation with technology, and in human-machine interactions. Thus, it is clearly an essential matter to understand the first person perspective of BCI users, as well as the outlook of potential users and other BCI stakeholders.

In the interest of gaining an overview of existing studies, we have conducted a scoping review of published studies related to BCI that make use of social research methods. This scoping review is "aimed at mapping key concepts, types of evidence, and gaps in research related to" the field of BCI research "by systematically searching, selecting and synthesizing existing knowledge" [23]. The following paper should serve as a basis for future empirical studies and inform conceptual and ethical deliberations. We include studies considering various BCI stakeholders as well as quantitative and qualitative methods of social research.

Methods

A comprehensive review of the literature regarding brain-computer-interfaces and social research methods was conducted by following the five stages outlined by Arksey and O'Malley [24]. According to Levac et al. [25], we integrated further aspects such as a tabularly summaries and qualitative thematic analysis.

We aim to identify and characterize key social aspects of BCI use. In particular, the intent of the paper is to retrieve and synthesize existing scientific data on the perspective of BCI users. The focus of the review is not on technological and medical issues, but on psycho-social, personal, and ethical aspects of BCI use. For that purpose we turn to studies that employ social research methods as these methods can be regarded as a standard for reliable research outcomes with respect to societal and psycho-social practices. Hence, we selected the method of a scoping review with the intent of exploring the extent of research on the topic, summarizing findings and identifying research gaps. Given that the body of literature available is quite extensive and heterogeneous, a scoping review of the social and human implications of BCI use helps create a comprehensible overview for future research in this area of emerging and urgent relevance. This means, at the same time, that the body of literature is "not amenable to a more precise systematic review" [26].

Sources

Six databases were systematically searched and analyzed, namely PubMed, EMBASE, PSYCINFO, PSYNDEX, Sowiport, and SocINDEX due to the wide coverage offered in BCI-oriented research (across fields of medicine, psychology, and social sciences.) From March 1st to May 3rd 2017, two researchers performed the search. Publications dated later than May 3rd 2017 were not included in the systematic research, but may be referred to in the discussion section of the paper. All existing articles which met our research criteria were screened. In light of the novelty of BCI technology we expected further forms of publications and thus identified additional literature through searches in local university libraries, other internet sources, and by cross-referencing. We have drafted an internal review protocol which was not registered.

Inclusion/Exclusion criteria

Following a research consultation, we agreed on the following rationale for searching the databases. Two primary search terms and seven cross-references were used:

- Search terms:
    ○brain-computer* OR brain-machine*
- Cross-references with:

  ○ case study OR empirical OR interview OR qualitative OR quantitative OR questionnaire OR survey.

The cross-references were used to identify research on BCI that utilise social research methods. The search was performed on “all search terms” or “MeSH” terms (Pubmed).

“Methods of social research are the *technical practices* used to identify research questions, collect and analyze data, and present findings” [27]. Social research methods can be differentiated into quantitative and qualitative methods. The latter aim at the interpretation of meanings people assign to their actions, the former seeks to discover regularities in social phenomena. Quantitative methods are associated with surveys, experimental methods and the use of statistics. Qualitative methods often make use of interviews, focus groups, case studies or ethnographies, as well as methods of coding, theme, discourse or narrative analysis [27].

We limited the search in this case to the most relevant terms for the review. General key terms that cover the broad spectrum of research methods (empirical, quantitative, qualitative) were combined with specific terms to prioritize data gathering methods (i.e. case studies, interviews, questionnaires, and surveys).

The search was limited to literature published in English or German, two major scientific languages spoken by researchers in the field. No restriction was applied regarding the date of publication up to the date of the search.

To illustrate this procedure, one electronic search strategy conducted via PSYCINFO we will describe here in detail. The primary search term ‘brain-computer*’ was combined with the cross-reference ‘empirical’ using the AND-function. No specific field was selected. Furthermore, the search options were adjusted by choosing the search mode ‘Find all my search terms’ and selecting the publication type ‘All’. Initiating the search resulted in 25 hits. This procedure was repeated for each search term (brain-computer* and brain-machine*) and each of the seven cross-references separately. In total the research in PSYCINFO yielded 188 hits.

Analysis

Figure 1 provides an overview of the review procedure according to the PRISMA flow diagram [28]. The initial database research yielded 510 records. In addition, further publications found online or via a snow-balling method were manually added ($n = 11$) at the first stage of the research process. After removing duplicates and applying the inclusion/exclusion criteria, we identified 73 relevant publications. All of these publications were retrieved as full texts and analyzed using thematic analysis. The results were summarized in an Excel file. Each selected publication has been summarized and listed in tabular form (see Additional file 1).[1] We assessed risk of bias through evaluating and discussing our findings within a team of researchers at regular intervals.

The studies were categorized according to subgroups, reflecting the different groups of study participants (potential users, actual users, professionals, caregivers). Due to the amount of studies with potential and actual users, these groups each were divided further into two subgroups according to the methods used in the studies (namely quantitative and qualitative methods). This process allowed for a comprehensible display of the results and a more concise comparison within and among the various groups. In a second step, themes were identified by means of inductive reasoning in the style of the Qualitative Research Synthesis approach from Claire H. Major and Maggi Savin-Baden [29]. The themes are displayed either as columns in the tables or as bullet points.

Results

The final synthesis of the search undertaken contains a total of 73 publications of which 45 report quantitative studies, and ten refer to qualitative studies. Eighteen studies used a mixed-methods approach encompassing both quantitative and qualitative methods. Of the 73 publications, 13 report on the perspectives of potential users, i.e. persons who may have had a particular interest in using BCIs, but had no actual experience with BCIs. Fifty-eight publications focus on persons who have experienced BCIs either before or during the very study of the respective publication. Five studies additionally encompass caregivers/relatives. Seven studies address experts/professionals.

As outlined above, we obtained four groups of user studies (categorized along the axes – quantitative/ qualitative studies and potential/actual users): quantitative studies with potential users ($n = 11$), qualitative studies with potential users ($n = 2$), quantitative studies with actual users ($n = 48$), and qualitative studies with actual users ($n = 21$). Studies employing mixed methods fall into both the quantitative and qualitative categories. Because of differences in terms of expectations and the impact of BCI among the users, the last category (qualitative studies with actual users) requires further differentiation. Accordingly, results of non-impaired users and users with physical impairments were assessed separately. The latter often are referred to in the BCI literature as “end-users”. (This terminology, however, could be quite confusing as not all BCI applications e.g. in the case of gaming, aim for persons with physical impairments as their end-users.)

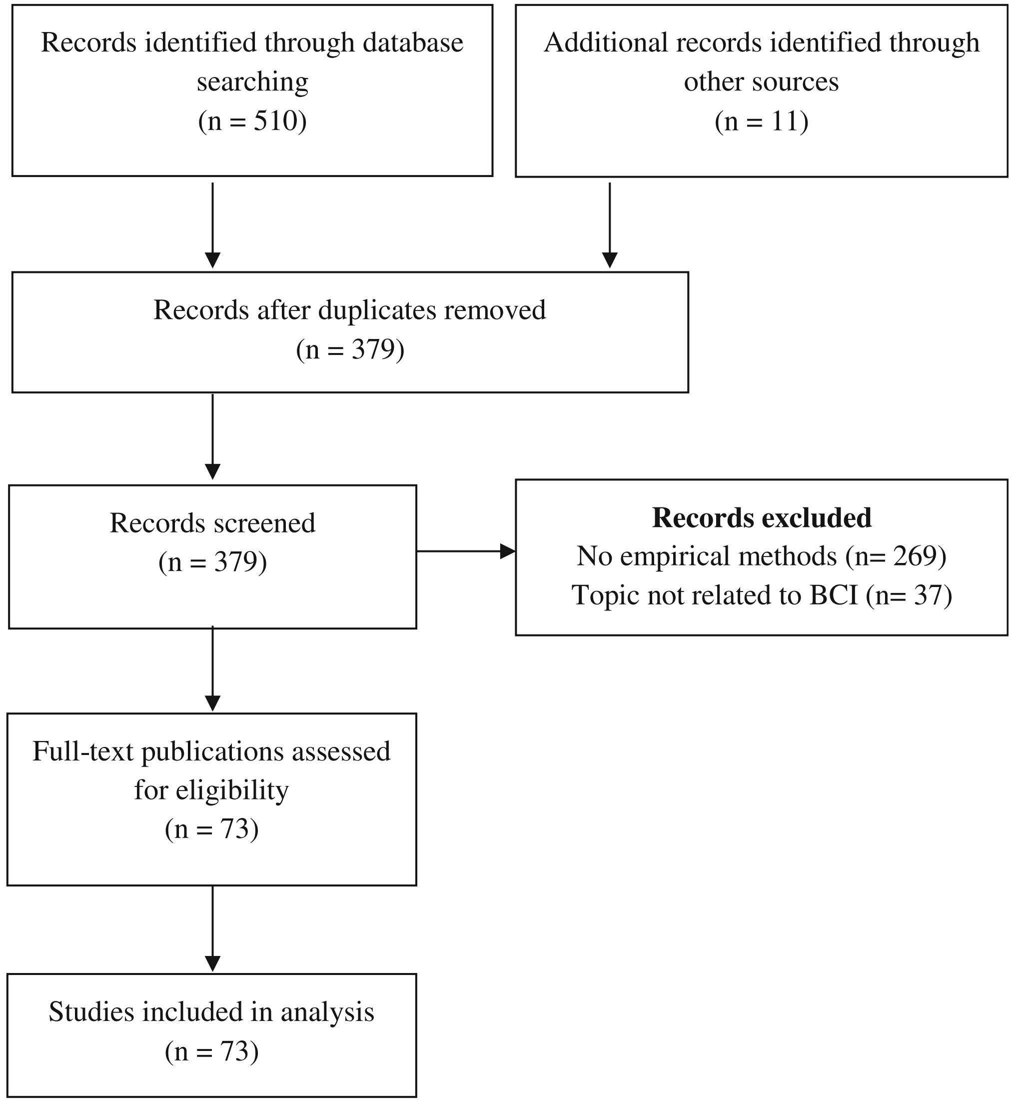

Fig. 1 The review process

Seventy-one of the 73 publications are focused on (potential or actual) BCI users. Two studies address BCI experts only. However, many of these 71 studies also encompass caregivers, experts, health care professionals or other BCI stakeholders.

Potential users

Research studies which have been conducted with potential users of BCIs mainly focus on assessing expectations that this particular group has about BCI as a so-called "assistive technology" device. These studies thus mostly limit these expectations to the question of the usability of the technology. The objective of such studies is to obtain information about the profile of the end-users for whom BCIs are being developed. The intent implicit therein is also to draw the developers' attention to aspects deemed important by potential users, in order to meet user demand and adapt the technology accordingly.

Quantitative studies

There are 11 studies included in the review which assess the opinion of potential BCI users by means of quantitative methods (surveys/questionnaires) (Table 1). Three of the included quantitative studies evaluate non-impaired participants. They assess preferences of gamers [12], test for control aspects in gaming [30], and work on selection strategies for BCI use [31]. Eight studies in contrast focused on the needs of persons with physical impairments. The impairment- or medically-focused studies evaluated the interest in BCIs among potential users, marking their preferences regarding different

Table 1 Studies with potential users employing quantitative research methods

Publication	Interest in BCIs	User preferences regarding BCI functions/features	Expectations towards BCI technology	Other aspects
Ahn et al., 2014 [12]		active and reactive BCIs		high potential of BCI; most potential fields: rehabilitation, prosthesis, gaming
Blabe et al., 2015 [100]		communication	ease of use, high performance, little maintenance, decent aesthetics	
Collinger et al., 2013 [101]		arm/hand and bladder/ bowel function	independent use, convenient use, non-invasiveness, functions, costs, set-up time	
Huggins et al., 2011 [88]	high, even for implants		accuracy, speed, simplicity, standby mode	
Huggins et al., 2015 [102]	high among persons with low functional independence	dry electrodes	better speed and set-up time	
Lahr et al., 2015 [103]	high, even for implants		knowledge about risks/rewards	
Kageyama et al., 2014 [89]	depending on severity of disease	communication	various control functions (TV, bed, emergency alarm)	
Pedrocchi et al., 2013 [104]			improve autonomy, home use, ease of use, be light and wearable	
van de Laar et al., 2013 [30]				testing control settings
Vuckovic/ Osuagwu, 2013 [31]				strategies for selecting promising BCIs
Zickler et al., 2009 [105]			functionality, independence (mobility, daily life activities, employment, ease of use)	

The table below portrays the variety of different research objectives the studies were focused on. An empty box indicates that the focus of the study was not on the theme addressed in the respective column but on others

features and functions, and requirements the technology is supposed to meet.

Qualitative studies

Only two studies assessed the opinions of potential users by means of *qualitative methods*. Klein et al. [32] set up a focus group and conducted telephone interviews with a total of 15 persons with implanted (open-loop) deep brain stimulation devices. The idea of BCI controlled closed-loop brain stimulation is met with acceptance among some potential users, while others feel ambivalent or opposed to the concept in principle. Comparing this hypothetical setting with the experiences of the study participants with open-loop brain stimulation, some participants welcomed the prospect of a self-controlled brain stimulation device while other participants maintained reservations. Some study participants expected an improved level of self-expression while others feared a distortion of their sense of self. The new brain stimulation device might also further restrain the user's sense of accountability, in the case that others would hold the device responsible for their behavior or expressions. Furthermore, this application would require more trust in researchers to keep their data secure and confidential. This last point concerns the issue of meaningful consent. Participants mentioned difficulty in understanding all risks and implications of a closed-loop device both for themselves and for individuals with cognitive impairments.

Schicktanz, Amelung and Rieger [33] conducted open interviews with ten persons with various chronic conditions (e.g. amyotrophic lateral sclerosis (ALS), muscle atrophy, para−/tetraplegia), to whom they presented a video about a motor-readout BCI that controls a robotic arm. Participants hoped for more independence, self-control, privacy/intimacy, and better communication. Some were concerned about data protection and abuse. Additional concerns raised include the creation of self-transcending human-machine hybrids, as well as the fear for further dependencies, as the BCI necessitates service support and technological maintenance.

Actual users

For this review, 58 studies focused on actual or real life BCI users and their experiences with the technology, usually stemming from experimental BCI studies that tested various BCI models in terms of their functionality and feasibility. The feedback from the study participants was largely limited to usability aspects. In most studies, the objective was to assess the opinion of the participants regarding the tested model and to gain information about what improvements need to be made.

Quantitative studies

Forty-eight studies evaluated the users' opinions or assessed various personal factors of BCI users by employing quantitative methods (mostly in the form of questionnaires). Twenty studies employed BCIs in non-impaired individuals, 17 studies tested BCIs in individuals with various physical impairments, and ten studies included participants from both groups. Most of these studies were concerned with the usability and feasibility of the technology. The performance of BCIs for users was assessed in aspects such as efficiency, effectiveness, and satisfaction. Furthermore, popular aspects assessed included cognitive or psychological factors, such as memory, attention, fatigue, mood, motivation, depression, and quality of life. Frequently applied tests were the NASA Task Load Index (NASA-TLX) for assessing subjective workload, the Quebec User Evaluation of Satisfaction with assistive Technology, Version 2.0 (QUEST 2.0) for measuring satisfaction, the Schedule for the Evaluation of Individual Quality of Life (SeiQol) for assessing the subjective quality of life, and the Questionnaire for Current Motivation (QCM) for testing the level of motivation. Performance was measured by the accuracy of the tasks, by the number of successful trials per session, or by means of the information transfer rate (ITR). Satisfaction was assessed via QUEST 2.0, visual analog scales (VAS) or the Assistive Technology Device Predisposition Assessment (ATD-PA) scale. Thematic aspects that were covered by the quantitative studies with actual users included:

- **Usability** [34–53] in terms of ease of use/difficulty [34, 41–43, 47, 51], fatigue/exhaustion [34, 35, 39, 41], usefulness [38, 40, 43], acceptance [36, 44, 45], comfort [48, 51], or safety [44, 45].
- **Performance** [11, 36–43, 48, 49, 51, 52, 54–73] measured as accuracy [36, 41–43, 48, 52, 54, 59–62, 70], ITR [42, 48, 73], subjective level of control [58], number of successful trials [63], or skill development [67].
- **Satisfaction** [38–40, 48, 51, 56, 58, 61–66, 69–72, 74] mostly assessed via VAS, QUEST 2.0, and/or ATD-PA.
- **Psychological factors** such as motivation [38, 42, 47, 50, 55, 57, 63, 66, 75, 76], mood [11, 32, 50, 63, 66, 68], depression [38, 50, 52, 63], memory and attention [42, 44, 45], concentration [42, 77], or motor/kinesthetic imagery [68, 69, 75].
- **Workload** evaluated as efficiency via ITR and NASA-TLX [38, 40, 56, 61, 62, 71, 72], NASA-TLX only [39, 47, 53, 57, 58, 63–66, 78, 79], Repeatable Battery for Neuropsychological Status (RBANS) score [44, 45], or VAS [51].
- **Quality of life** measured via SEIQol [38, 50, 56], the Anamnestic Comparative Self-Assessment (ACSA) [38, 56] or the Psychosocial Impact of Assistive Devices Scale (PIADS) [39, 40] (some use PIADS for measuring user satisfaction, not quality of life, e.g. Vansteensel et al. [74]).
- Other aspects addressed were presence [54, 55, 70], knowledge, purpose of use, and future visions [80], plasticity and body projection [54], control/self-regulation [59, 73], comfort of (dry) electrodes [60], engagement [53], novelty [48], and physical state [11].

These aspects were assessed for non-impaired participants as well as for participants with physical impairments. Quality of life was measured among the latter only.

Qualitative studies

Altogether from the qualitative studies evaluating BCI users' perspectives, 21 studies emerged. Most of the qualitative studies used interview studies or focus groups. Several also opted for observations [81, 82] or discourse analysis [33]. One study focused on non-impaired participants only [54], 16 studies on participants with physical impairments, and four studies on a mixed population. In the breakdown of mixed methods studies, there are five studies including non--impaired participants (Table 2) and 20 studies with participants with physical impairments (Table 3). The objective of such qualitative studies was to improve and develop the technology of BCI as well as to embrace a medico-technological approach. Hence, qualitative data gaining methods were used for this purpose only. The studies which did not specify any qualitative data analyzing methods mostly ran statistical analyses and addressed the qualitative data as secondary [10, 36, 38, 40, 46, 49, 54, 56, 61, 62, 71, 72, 81, 83, 84]. Certain studies aimed also to address ethical aspects related to BCIs [83, 85–87]. Şahinol [82] researched BCIs as part of a genuine sociological study including elaborated sections about the methods employed in the technology's use. Her study describes the mutual adaptation process between human and machine, resulting in the figure of a techno-cerebral subject.

Themes that were assessed included opinions (judgements and attitudes) towards BCIs, or issues that arose during BCI testing. Others related to requests from the

Table 2 Studies with non-impaired participants employing qualitative research methods

Publication	Data gaining methods	Data analyzing methods	Number of participants	Opinion towards BCI	Requests from technology	Others
Carmichael/ Carmichael, 2014 [83]	"participatory research"	none specified	10	uncertainty towards technology due to its novelty and tentative nature	more information	issues reported: cap, electrodes
Friedman et al., 2010 [54]	semi-structured interviews	none specified	10 + 3 (2 studies)			experiences of transparency of activities, sense of "presence" in VR, imagination of avatar as being (part of) themselves
Heidrich et al., 2015 [81]	participant observation	none specified	not specified	enjoyment	more efficiency	
Lightbody et al., 2010 [46]	workshops, interviews	none specified	not specified	no discomfort regarding caps	more aesthetic and practical cap, integration of other devices and entertainment system, improvements in terms of handling difficulty and graphics	
Mulvenna et al., 2012 [49]	focus groups, interviews, interactive workshops	none specified	23 + 17 (2 studies)	satisfaction, appreciation		

technology itself, such as aspects regarding social relations, quality of life, personality, and future BCI use.

Unlike non-impaired participants, persons with physical impairments have certain expectations of BCIs. Those affected by physical impairment tend to hope for more independence and social participation and expect from BCI use an increased quality of life. Some studies recognized the potential of BCI use to contribute to the user's self-esteem and self-expression. BCIs are reported as bringing satisfaction and enjoyment, although space for improvement certainly remains in this area.

Other BCI stakeholders

Aside from the users themselves, BCI studies also often feature inquiries into the experience of relatives, caregivers, assistants, BCI professionals, developers, health care professionals or company representatives. Expert studies consisting of BCI professionals, game developers, and therapists/health care professionals are either focused on the potential and ethical aspects of BCI (BCI professionals) or on requests and concerns regarding BCI (therapists/health care professionals) (Table 4). These external stakeholder opinions are often addressed only marginally and sometimes are not displayed separately from the users' perspective. A recurring group of stakeholders are caregivers (and/or relatives/assistants). Their participation forms part of focus groups or compliment the user's perspective (Table 5). Their opinions hardly are presented separately from other results.

Discussion

The systematic search presented in this review offers an outline of BCI research which employs social research methods (in all of its methodological and thematic variety.) The occurrence of empty boxes in the tabular displays above indicates the heterogeneity of the BCI studies found. Some studies focus upon and include specific aspects studied, while others concentrate on divergent aspects.

Prominent topics within BCI research have been highlighted and research gaps identified. The majority of the studies addressed are concerned with the usability and feasibility of BCIs. This provides valuable and necessary knowledge for BCI professionals to improve and optimize use of the technology. Potential users in the studies examined point out requirements they would expect of BCIs, such as standards of speed, efficiency, and ease of use. BCI use should improve their overall situation and not place an extra burden on relatives or caregivers. The general level of satisfaction that BCIs experience among actual users proves that current technological development is likely on the right track. Actual users are able to pinpoint more specific aspects which may inspire further innovation. Besides the several points addressed by potential users, there was additional mention of a more appealing design of EEG caps, a preference for dry electrodes, the integration of particular devices (e.g. TV, phone), and a stress placed on the importance of home-based use.

Apart from the conceptual disparities between the different studies mentioned above, further difficulties arise

Table 3 Studies with participants with physical impairments employing qualitative research methods

Publication	Data gaining methods	Data analyzing methods	Number of partici-pants	Opinion towards BCI	Issues reported	Requests from technology	Social relations	Quality of life	Personality	Future BCI scenarios
Andresen et al., 2016 [106]	interviews	thematic analysis	8			discussion limited to naming techno-logical dimensions (function, design, support) which are deemed to be of relevance	importance of social participation and communication (discussion is not directly linked to BCIs)			
Blain-Moraes et al., 2012 [90]	focus group	mix of qualitative methods (content analysis, thematic analysis)	8	offering freedom, hope, connection, independence; comfortability of learning to use the technology	mental and physical fatigue, anxiety, pain/ discomfort	comfortability, ease of use, enabling communication and interlinkages to TV and phone; use in home environment; dignifying appearance	worries regarding surplus-work effort for caregivers, but also provides caregivers with more time while using BCI			
Brown et al., 2016 [84]		semistructured interviews	none specified	1 (5 inter-views)		with implant: feeling self-conscious, irritation about usage; difficulty of control	less expensive (batteries)			complexity of BCI use is at odds with the user's "simple" and "easy-going" self-image
Carmichael/ Carmichael, 2014 [83]	"participatory research"	none specified	8	uncertainty towards technology due to its novelty and tentative nature	cap, electrodes, frustration about BCI illiteracy	more information	participation in and contribution to research progress and technology development			
Cincotti et al., 2008 [36]	interactive discus-sions, interviews	none specified	14			home use	preference for front door opener reflects will to determine who can play a part in their social lives	raising quality of life if being used at home		
Grübler et al., 2014 [85]	semi-structured interviews	qualitative content analysis (referring to Grounded Theory Method-ology)	19	expecting physical improvement, supporting science, curiosity towards technology, overall satisfaction with BCI testing; feeling astonished about BCI control	discomfort and annoyance (prep-arations and electrodes), burden of transportation, fatigue, disappointment/anger (about failure)	data security			moments of self-experience	BCIs are deemed to be impractical for everyday life use; no need for regulating BCIs

Table 3 Studies with participants with physical impairments employing qualitative research methods *(Continued)*

Publication	Data gaining methods	Data analyzing methods	Number of partici-pants	Opinion towards BCI	Issues reported	Requests from technology	Social relations	Quality of life	Personality	Future BCI scenarios
Grübler/Hildt, 2014 [87]	semi-structured interviews	(same as in Grübler et al. 2014)	19 (same as in Grübler et al. 2014)						varying opinions regarding (1) forming a functional unit with the BCI and (2) being able to forget about the technology while using it	
Heidrich et al., 2015 [81]	participant obser-vation	none specified	not specified	enjoyment		more efficiency				
Hildt, 2014 [86]	semi-structured interviews	(same as in Grübler et al. 2014)	same as in Grübler et al. 2014						varying opinions regarding (1) forming a functional unit with the BCI and (2) being able to forget about the technology while using it	
Holz, 2015 [38]	semi-structured interviews	none specified	4 + 4 + 2 (three different studies)	provides joy and happiness				provides opportunities for creativity and self-expression		
Holz et al., 2013 [56]	semi-structured interviews, focus group	none specified	4	BCIs for daily use are desirable given the technology improves	more training required	technical improvements, additional functions (e.g. "undo-function")				
Holz/Botrel/Kübler, 2015 [40]	personal statements	none specified	2	fun, happiness	increased dependence on others		participating on social public life through art exhibitions	self-esteem, expression of creativity, satisfaction		
Kübler et al., 2013 [61]	open interviews	none specified	17		set-up time, cap (comfort and look), need for washing hair after training, limited mobility, low speed					
Kübler et al., 2014 [62]	interviews	none specified	19		set-up, gel/cap, speed					ease of use and higher speed are

Table 3 Studies with participants with physical impairments employing qualitative research methods *(Continued)*

Publication	Data gaining methods	Data analyzing methods	Number of partici-pants	Opinion towards BCI	Issues reported	Requests from technology	Social relations	Quality of life	Personality	Future BCI scenarios
										imperatives for daily BCI use
Lightbody et al., 2010 [46]	workshop, interviews	none specified	15	satisfaction, preference for testing communication functions	discontent with phone function	control of technical devices (especially TV), better ease of use	being part of research team			potential for providing more engagement and participation
Mulvenna et al., 2012 [49]	focus groups, interviews, interactive workshops	none specified	20 + 11	satisfaction, appreciation						
Şahinol, 2016 [82]	ethno-graphic field work (passive and participant obser-vations, video and audio materials, in-depth interviews)	Grounded Theory Methodology	6 (interviews with study partici-pants)		physical and mental strains, frustration, belied expectations, pain		participation in studies as a pastime		on the one hand: sense of agency, cooperation with machine; on the other hand: uncertainty about causes of actions (self or machine), feeling of objectifycation due to being a study participant	
Salisbury et al., 2016 [10]	semi-structured qualitative questions	none specified	25	enjoyment						
Zickler et al., 2011 [71]	open interviews	none specified	4			control of wheelchair and other devices				daily use would require improvements regarding the cap, the ease of use, the size of the hardware, speed, and additional control opportunities
Zickler et al., 2013 [72]	semi-structured qualitative questions	none specified	4	enjoyment	gel induced skin problems, set-up time	improvement of the matrix, integration in other AT devices		creative expression		daily use would require less electrodes and no cable and appropriate service support

Table 4 Studies with experts/professionals

Publication	Methods	Number of participants	Interest in BCI technology	Opinion towards BCI	Requests from BCI	BCI potential/future
Ahn et al., 2014 [12]	questionnaire	36 game developer, 90 researchers	developers prefer active and reactive BCIs, researchers prefer reactive BCIs	developers are more concerned about the user's opinion in contrast to the researchers		high potential of BCI and BCI games; further potential fields: in particular rehabilitation and prosthetics
Grübler et al., 2014 [85]	survey	17 BCI professionals		ethical concerns reported: the duty of correct information transfer, avoiding unrealistic expectations in participants, BCI illiteracy, the risk of detrimental brain modifications due to BCI use and privacy issues		
Morone et al., 2015 [63]	focus group + questionnaire	15 therapists		acceptance among therapists depends on their respective technical competence and attitude; skepticism about precondition of technical knowledge/skills	future BCIs would require more goal-oriented feed-back and spasticity monitoring	
Nijboer et al., 2013 [107]	survey	145 BCI professionals		disagreement regarding terminology/ definitions of BCIs and marketability of different BCIs; ethical concerns reported: informed consent, benefits/risks, team responsibility, consequences, liability/ personal identity, and interaction with the media; non-invasive BCIs are estimated as being of low risk (indecisive about invasive BCIs); most BCI professionals hold the view that BCI users are responsible for their actions, while being uncertain regarding issues of liability; the effect of BCI activity on personal identity and self-image on the users are deemed to be unclear		
Nijboer et al., 2014 [108]	survey + focus group	28 rehabilitation professionals (focus group: $n = 28$, survey: $n = 18$)	the professionals ascribed no added value to BCI technology		human problems and practical issues should be taken into consideration	potential BCI users are identified as those who possess intact cognition and have no extant physical or sudden movements (seizures, spasms) which can cause problems
Pedrocchi et al., 2013 [104]	focus group	14 experts (mostly health care professionals)			reproduction of natural movements, ease of use, capability of multitasking, affordability	
Zickler et al., 2011 [71]	questionnaires	3 assistive technology experts		setting too complex, setup time to long, long selection procedure, restricted mobility, prone to body movements	improved cap and gel solution	BCI as promising tool for the future

Table 5 Studies with caregivers/relatives

Publication	Methods	Number of participants	Points addressed
Andresen et al., 2016 [106]	qualitative interviews	7 caregivers (paid und unpaid/ family caregivers)	esp. Quality of Life and AT-use emerged as major themes (results not separate from user study, see also Table 3)
Blain-Moraes et al., 2012 [90]	focus group (with users)	9 caregivers	BCI is regarded as an opportunity to maintain communication between caregivers and caretakers; caregivers would appreciate the opportunity of "back communication" (i.e. informing their caretakers, e.g. letting them know that they are on their way); caregivers also see an additional burden in dealing with the BCI (see also Table 3)
Geronimo et al., 2015 [37]	surveys (before and after testing)	41 caregivers	caregivers ranked BCI functions similar to their caretakers: priority of accuracy, variety of functions, standby reliability, wheelchair and computer control (results not separate from user study, see also Table 3)
Holz et al., 2013 [56]	focus group	3 caregivers (only featured)	focus group describes barriers for BCI use (physical, psychological, social) and its potential (freedom, independence)
Liberati et al., 2015 [91]	focus group	2 relatives + 6 caregivers and/ or health professionals	reported expectations towards BCIs: information about BCIs and their applications, a system that adapts to the various stages of the disease, taking account of emotion, and retaining the users' sense of agency

when considering the huge variety of participant groups, not only between non-impaired and impaired individuals, but also with regard to the multitude of conditions seen among the participants with physical impairments. As the majority of studies contained a mixed sample of participants with various physical impairments, specific conclusions hardly can be drawn for BCI use for particular conditions. Only a handful of studies examined persons with a singular type of impairment (often in case studies with a single participant). These impairments included stroke [57, 63], cerebral palsy [67, 81], and essential tremor [84]. The exception thus is a total of 12 studies solely (or in combination with non-impaired participants) conducted with persons having ALS [37, 39–41, 50, 58, 59, 74, 88–91]. These results do not differ significantly from the other studies. One difference might be that persons with ALS (especially those in advanced stages) show a higher degree of interest in BCIs. This may be explained by the dismal outlook for mobility from this disease, which gradually robs patients of the ability to move their limbs, communicate verbally and interact with their environment, approaching a state of locked-in syndrome. In other conditions, patients may retain certain motor functions of their body that may allow them to use other technological devices, such as peripheral neuroprostheses. Few studies have been conducted with BCI professionals.

Very little interest has been placed so far on the experiential dimension of BCI users beyond usability aspects. Where the BCI literature examines "user experience" - sometimes simply called "UX" [47] - or pursues a user-centred approach, the respective studies apply psychological factors like mood, motivation, or depression, the participants' quality of life, satisfaction, their opinions, judgements, and requests to BCI use. In contrast to the user's experience with BCI, the user's experience *of* BCI has been hardly researched. This outlook would comprise questions towards BCI use from the point of view of philosophy and social sciences, broadly describable as the *What is it like?* – perspective. What is it like to use a BCI? What is it like to act by using a BCI? And therefore: What is it like to act without using my body? What is it like to be hooked up to a machine or computer? Is it (still) me that is acting within this BCI system or is it some kind of human-machine hybrid? These are questions that address topics like agency, autonomy, responsibility, accountability, self-image, identity, hybridization, or artificial intelligence.

Dealing with these questions will be of major relevance, not only because the BCI relies on a new form of connection between human and machine, but also because the technology produces bodily experiences the user would not have otherwise. For example, performing an action without moving a body part opposes our common understanding and sensation of being an agent and can manifest itself as a new experience.

First attempts in this direction have been made by Grübler and Hildt [85–87]. Their research study raised the question of transparency, i.e. the ability to operate a tool without having to consciously apply its operating instructions. Applied to the example of BCIs, this would mean operating a BCI without focusing on a mental strategy. The study in question also asked participants whether they felt themselves to be a part of a functional unit with the computer. Some participants reported experiencing transparency, but fewer participants reported having felt being a part of a functional unit with the computer. The authors postulate a discrepancy between these two judgements.

Şahinol [82] points to several aspects related to the sense of agency and shared agency with the computer, revealing uncertainties among the users about how to make sense of BCI activities. The objective of Şahinol's study, however, is about the adaptation process between humans and machines and therefore does not elaborate on the subjective user perspective regarding these aspects. Two studies published after the completion of our data collection and review, specifically by Gilbert et al., questioned users with implanted BCIs for the treatment of epilepsy. These studies yielded valuable insights regarding control and self-perception [92] as well as autonomy and deliberation processes [93]. This step would be crucial in working to close the research gap outlined above.

Among studies with BCI professionals, the focus lies on ethics. Crucial areas of inquiry like informed consent, managing users' expectations, and psycho-social consequences of BCI use are explored. Another recent study, conducted by Specker Sullivan et al. with neural engineers [94], was directed towards an improved sensitization of the inclusion of users in the development process of BCIs. The user-centred design endorsed in the paper is present among various studies of this review's body of literature [38, 57, 58, 62, 72, 91]. Therapists and health care professionals are skeptical about BCIs and require certain improvements of the technology. Caregivers' perspectives resemble users' opinions. A study focusing on caregivers only, however, has not been conducted so far.

As most of the studies discussed in this article are guided by a medico-technological approach, ethical issues are hardly being addressed and under-researched. This observation about the field of inquiry in BCIs is discussed in detail by Specker Sullivan and Illes [95]. When ethical aspects are addressed, it is in accordance with the ethical aspects addressed in the ethics literature, as shown by Burwell et al. [96]. Matters such as autonomy, agency, personality, safety or privacy are comprised.

Our own team of researchers encourages more empirical work on these matters. While philosophical in nature, matters such as agency, autonomy and responsibility are also highly relevant for legal and policy-making affairs. This particularly depends on the part the user plays within the loop of the BCI, and its data collection. Particular closed-loop neuro devices such as closed-loop DBS modulate stimulations outside the awareness of the user and therefore cause moral and legal issues of accountability [97]. In BCIs the user receives feedback in some form (visual, auditory or haptic). She usually is nominally aware of this feedback and is given the opportunity to react to it deliberatively. The user "stays in the loop" even at least partly when connected to some autonomous system and hence gives rise to a different situation of accountability [98]. To evaluate these aspects in practice would yield important insights to inform moral, legal and political debates.

Limitations

This study has several limitations. First of all, a scoping review cannot guarantee that all scientific literature is exhaustively found and analyzed. The literature output is confined to studies that explicitly study brain-computer- or brain-machine-interfaces or imply one of the terms as a key term. Some technologies that are labelled under "neurofeedback", "closed-loop" or "predictive brain devices" may also qualify as brain-computer-interfaces. However, as not all of these are de facto brain-computer-interfaces and to keep the task at hand feasible, we confined our search to the search terms brain-computer* and brain-machine*. For the same reason we disregarded comparisons to other technologies such as open-loop deep brain stimulation which may render comparable results (e.g. [99]). Among the studies examined, we added manually some publications (books and book chapters) which are not peer-reviewed publications.

In order to manage the total search outcome of 73 publications, various differentiations have been neglected and need further examination: BCI varies widely in terms of its technical set-up, of which each application and model would require particular attention, e.g. in terms of measurement (invasive - non-invasive, EEG, NIRS, fMRT, ECoG, or others), mental strategy (selective attention, motor imagery), stimuli set-up (visual, auditory, haptic), application (communication program, prostheses, computer game, or others), or type of neurofeedback (displayed on monitor, successful movements, or others). Also comparisons between non-impaired participants and participants with physical impairments as well as between different impairments deserve more detailed attention. The scoping review method is a useful tool to map and synthesis large bodies of literature which comes at the expense of a detailed analysis of the results. The various themes identified in this review therefore deserve a further, elaborated examination.

Conclusion

A great deal of research has been conducted on the perspectives of potential and actual BCI users. These opinions, and emerging social research data, are key in advancing the development of user-appropriate, humane, and successful BCI technology. BCIs have much to offer: the ability to increase quality of life, enhance social life, and contribute to a higher level of self-determination and independence for persons with physical impairments. At the same time, this technology can lead to impingements on human autonomy, psychological frustration, the creation of dependency, and the causing of confusion regarding user self-perception. The qualitative self-experience of BCI users, i.e. aspects related to personal identity, agency, and responsibility, has hardly been examined thoroughly. This is due to the delicate and demanding nature of this research as well as a limited number of study participants until now. Nonetheless, as questions regarding the experience of BCI users are crucial for evaluating ethical and societal aspects of an emerging technology, more empirical research on these matters is deeply encouraged by researchers involved.

Endnotes

[1] The list in the Additional File is categorized according to research interest, methods, number of participants, BCI testing, BCI type, and results. These categories have been chosen to render a comprehensible overview of the body of literature. The purpose of the categorization is to serve as a helpful tool to the researchers, it is not part of the analyzing method applied and outlined in the review.

Additional file

Additional file 1: List of all 73 studies examining BCIs by means of social research methods. Studies are listed regarding research interest, methods, number of participants, BCI testing, BCI type, and results. (DOCX 44 kb)

Abbreviation

BCI: Brain-computer interface

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Availability of data and materials

All data generated or analyzed during this study are included in this published article and its supplementary information files.

Authors' contributions

All authors contributed to study design and planning. JK and JS conducted the literature searches, organized and analyzed collected references. JK, JS and OF wrote different sections of the article. RJ and OF provided review of analysis results and suggested revisions for the write-up. All authors reviewed and approved the manuscript.

Ethics approval and consent to participate

Not applicable.

Consent for publication

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Competing interests

JK, JS and OF declare that they have no competing interests. RJ is member of the Editorial Board for BMC Medical Ethics.

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