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Published in:
Sexuality and Disability

DOI:
[10.1007/s11195-013-9298-4](https://doi.org/10.1007/s11195-013-9298-4)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Final author's version (accepted by publisher, after peer review)

Publication date:
2013

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Verschuren, J. E. A., Geertzen, J. H. B., Enzlin, P., Dijkstra, P. U., Dekker, R., & Van Der Sluis, C. K. (2013). Addressing Sexuality as Standard Care in People with an Upper Limb Deficiency: Taboo or Necessary Topic? *Sexuality and Disability*, 31(2), 167-177. <https://doi.org/10.1007/s11195-013-9298-4>

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Addressing Sexuality as Standard Care in People with an Upper Limb Deficiency: Taboo or Necessary Topic?

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Published online: 9 April 2013
© Springer Science+Business Media New York 2013

Abstract The purpose of this paper is to analyze whether professionals who work with people with an upper limb deficiency (ULD) received questions about sexuality from their patients and whether they addressed sexuality themselves, and to analyze their knowledge and comfort level, approach and attitudes towards sexuality. An online questionnaire, including questions on self-perceived sexological competence and the Knowledge, Comfort, Approach and Attitudes towards Sexuality Scale (KCAASS) was used to assess these aspects. One out of three professionals had received a question about sexuality from their patients. Nearly one out of five professionals had addressed sexuality themselves. Professionals who received a question about sexuality from patients or addressed this issue themselves had significantly higher scores on self-perceived knowledge about sexuality and on self-perceived conversation skills compared to professionals who did not. The scores on the KCAASS Knowledge and Comfort of professionals who received a question about sexuality or addressed the issue of sexuality were significantly higher than those of professionals who did not. Sexuality is thus only scantily discussed by professionals working with patients with an ULD. Professionals indicated they do not feel confident nor comfortable enough to address this issue. They also experience a lack of appropriate knowledge to address sexuality with patients. Professionals reported a need for courses and training on both knowledge and conversation skills concerning sexuality. In addition, a

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protocol and necessary facilities need to be provided for the team working with people with an ULD in order to be able to address sexuality systematically.

Keywords Amputation · Upper extremity · Sexuality · Rehabilitation · The Netherlands

Introduction

In the Netherlands, about 60 amputations of an upper limb (proximal from the wrist) are performed each year [1]. Most acquired upper limb amputations occur as a result from a trauma. Additionally, every year about 20 children are born with a major congenital transverse reduction defect of the arm [1]. In this paper, the term ‘upper limb deficiency’ (ULD) is used for both entities.

An ULD imposes multiple specific challenges on the individual. Several daily activities such as driving a car or personal hygiene care are not easy to perform with just one hand or arm.

Hands and arms, however, do not only play an important role in daily practical activities, they are also crucial in social communication and human interaction [2]. Indeed, they are used for expression, communication and affection [3]. Some people even consider the hand to be a person’s most individual and personal body part [4]. Moreover, as sexuality is based on interaction and touching, hands and arms may also play a crucial role in this domain that is contributing to quality of life of both men and women. When someone is missing an arm or a hand, stroking and caressing their partner and/or masturbation may be hindered [5]. It has been suggested that due to both the physical and psychological consequences of a limb deficiency also other sexual problems, such as a decrease in sexual interest, problems with sexual arousal and/or orgasm, may occur as well [5–8]. However, in rehabilitation medicine in general and more specifically in rehabilitation care for people with an ULD little attention is being paid to the possible occurrence of sexual problems [9]. This is regrettable because sexuality is considered to be a basic human right—also for patients with a disability or chronic disease [10, 11], and thought to be an important need for most people and in most relationships [12]. Moreover, a satisfactory sex life may have a positive influence on patients’ physical health, longevity, pain management and immunity [10, 11].

Despite this information about the importance of sexuality for ULD patients, many professionals in rehabilitation settings report that they do not feel comfortable discussing sexual issues with patients [13, 14]. They refer to a lack of time, a lack of knowledge and missing the relevant skills to initiate a conversation about sexuality with their patients as reasons for not addressing sexuality with their patients [6, 13, 15]. While there is some research on communication about sexuality on professionals working with people with diabetes, cancer or spinal cord injury [16–20], little is known about the specific situation of professionals who work with people with an ULD.

Therefore, the aim of this study was to analyze whether sexuality is discussed by professionals who work with people with an ULD, and, if so, who takes responsibility for initiating this. Our research questions were the following: (a) do professionals receive questions about sexuality from patients; (b) do they address sexuality with patients themselves; (c) is the way professionals perceive themselves in terms of sexological competence associated with receiving questions from patients and with addressing sexuality by these professionals; (d) is the professional’s knowledge and comfort level,

approach and attitudes towards sexuality associated with receiving questions from patients and with addressing sexuality by these professionals?

Methods

Participants

Participants were recruited through the Working committee ‘Amputation and Prosthetics of the Arm’ (WAP-A) of the Netherlands Society of Physical and Rehabilitation Medicine (Nederlandse Vereniging van Revalidatieartsen; VRA). Nearly every professional working with people with an ULD in the Netherlands is a member of the WAP-A. Some members are employed in Flemish rehabilitation centers and/or hospitals.

Questionnaire

The questionnaire used in this study was previously used to evaluate rehabilitation professionals’ training needs concerning communication about sexuality with patients [21]. This questionnaire was slightly adapted, making questions and scenarios suitable for professionals working with adults and/or children with an ULD. Professionals who only worked with children with an ULD could also fill out the questionnaire, however, some of the questions were not relevant for their patient group.

The questionnaire consisted of two major parts. In the first part, demographic characteristics of the professionals such as age, gender, discipline, amount of employment and sexuality related training were collected. The first part further focused on sexuality related communication (asking or receiving questions in the last 6 months) of professionals working with people with an ULD and on the way professionals perceive themselves in terms of sexological competence. This self-perceived sexological competence consisted of three aspects: knowledge, recognition of sexual problems and conversation skills. These three aspects were separately scored on a 10-point scale, with anchors 1: hardly any knowledge/skills and 10: excellent knowledge/skills. This part of the questionnaire was concluded with three open questions about attention for sexual problems of patients with an ULD, the physical possibilities (e.g. time, a room with enough privacy) to address sexuality and about prescribing a limb prosthesis for sexuality related reasons.

The second part of the questionnaire consisted of a Dutch translation and adaptation of the Knowledge, Comfort, Approach and Attitudes towards Sexuality Scale (KCAASS). The KCAASS was originally developed to measure training needs concerning sexuality of professionals working with patients with a spinal cord injury [15]. The original KCAASS is a validated instrument. It measures the professionals’ knowledge and attitudes about sexuality, as well as their comfort with and approach towards sexual issues in their patients [15]. The KCAASS consists of 4 scales, i.e. Knowledge (scale range 14–56), Comfort (scale range 18–76), Approach (scale range 5–20) and Attitudes (scale range 4–16). As mentioned above, the questions and scenarios of the original questionnaire, including the KCAASS, were slightly adapted to make them suitable for professionals working with people with an ULD. In this study, the KCAASS consisted of 42 questions and scenarios. The item scores related to the Knowledge scale were summed. The item scores related to the scales Comfort, Approach and Attitudes were reversed before being summed up [22]. Higher scores represented better knowledge and skills.

Procedure

A link to the online questionnaire was sent to the secretary of the WAP-A. She forwarded this link to all members of the WAP-A. In order to enable calculation of the response rate, the secretary was asked to provide the number of professionals the link was sent to. On the annual WAP-A conference day, the study was promoted and questionnaires on paper were available for those professionals who accidentally did not receive the link to the online questionnaire, or who wished to fill out the questionnaire during that day.

Statistics

Data analysis was performed using PASW Statistics (SPSS) for Windows version 19.0. Descriptive statistics and non-parametric tests were used. χ^2 (method: exact) and Fisher's exact tests were used to analyze differences in the distribution of scores of professionals who addressed sexuality and those who did not. Mann–Whitney *U* tests were used to analyze differences in mean scores between professional groups. A two-sided *p* value of .05 or less was considered to indicate statistical significance.

Ethical Approval

Since the questionnaire used in this study was directed towards professionals, approval from a medical ethics committee was not required.

Results

Professionals' Characteristics

In total, 62 professionals received the link to the online questionnaire or had the opportunity to fill out the questionnaire on paper. Thirty-seven professionals completed the first part of the questionnaire. One professional completed most of the first part of the questionnaire, but did not fill out the questions concerning self-perceived sexological competence and further. In total, 33 professionals started filling out the second part of the questionnaire (the KCAASS questionnaire). Twenty-nine professionals completed the entire questionnaire (response rate 47 %) (Table 1). The reasons for not completing the entire questionnaire were not investigated.

Sexuality Related Communication of Professionals Working with People with an ULD

Regarding the questions about sexuality related communication, professionals were asked to reflect on the period of 6 months prior to filling out the questionnaire.

Almost one third of the professionals (11/37) reported to have received a question about sexuality from their patients. Nearly one out of five (8/37) reported to have addressed sexuality with their patients. Professionals who did address the issue of sexuality with their patients, were significantly more likely to have received questions about sexuality from their patients than those who did not address this issue. These professionals were also significantly more likely to perceive addressing sexuality as rather easy to do. Moreover, they were also more likely to consider addressing sexuality to be part of their job description (Table 2).

Table 1 Characteristics of the professionals who completed the first part (n = 37) and the entire questionnaire (n = 29)

Characteristics	Completed first part (n = 37)		Completed entire questionnaire (n = 29)	
	n	%	n	%
Mean age (\pm SD)	43.6 (\pm 11.3)		43.4 (\pm 10.8)	
Gender				
Male	16	43	12	41
Profession				
Medical	8	22	7	24
Paramedical	18	49	16	55
Perimedical	1	3	0	0
Prosthetist	10	27	6	21
Fulltime employment	13	46	13	45
Some form of sexuality related training	9	24	8	28
Patient group				
Children (\leq 18 years of age)	9	24	5	45
Adults	17	46	16	55
Children and adults	11	30	8	28

Medical rehabilitation doctor, rehabilitation doctor in training, *paramedical* physical therapist, occupational therapist, *perimedical* psychologist, social worker, psychotherapist

Table 2 Sexuality related communication of professionals working with people with an ULD (n = 37)

	Addressed sexuality in the past 6 months		p
	Yes (n = 8)	No (n = 29)	
Professionals receiving questions from patients			<.001*
Yes (n = 11)	8	3	
No (n = 26)	0	26	
Addressing sexuality perceived as			.001**
Very easy (n = 0)	0	0	
Rather easy (n = 3)	3	0	
Neutral (n = 22)	5	17	
Rather difficult (n = 11)	0	11	
Very difficult (n = 1)	0	1	
Discussing sexuality is part of my job description			.003**
Definitely (n = 7)	4	3	
Probably (n = 13)	3	10	
Neutral (n = 4)	1	3	
Rather not (n = 9)	0	9	
Not at all (n = 4)	0	4	

* Fisher's exact test

** Exact procedure, linear-by-linear association

Five out of 37 professionals reported to have referred a patient to another discipline for a sexual problem. Six professionals reported that sexuality or sexual problems of patients were formally discussed in team meetings. Two professionals reported that it was formally discussed during discipline group meetings. Informal discussions about sexuality in team meetings or discipline group meetings were reported by respectively eight and four professionals.

Nine professionals stated that there were too few physical possibilities (e.g. time, a room with enough privacy) to discuss sexual issues of patients within their team or discipline group. Too little attention for patients' sexual problems was reported by 23 professionals while 17 professionals found that the quality of attention paid to sexuality was inadequate. In response to the open question about how attention for sexuality could be improved in their work setting, the majority of the professionals stated that the most important way to improve attention for sexuality would be to systematically address sexuality with patients and within the team (meetings). They also mentioned that more knowledge about sexual problems of patients with an ULD is indispensable to recognize these problems and that they needed training in how to address sexuality.

Two professionals reported to have prescribed a limb prosthesis for sexuality related reasons. The other professionals did not prescribe such a prosthesis for different reasons: 'because patients did not ask for a prosthesis for that reason'; 'prescribing prostheses was not a part of the job description of the professional'; 'having sex is more comfortable without a prosthesis'; and 'insurance companies do not cover the costs for such a prosthesis'.

Self-Perceived Sexological Competence

The mean (\pm SD) self-perceived knowledge about sexuality in the context of disability and chronic disease of all professionals was 4.9 (\pm 1.7). The means (\pm SD) of the professionals' self-perceived recognition of sexual problems and conversation skills were 4.7 (\pm 1.7) and 5.3 (\pm 1.7) respectively.

Knowledge, Comfort, Approach and Attitudes Towards Sexuality Scale (KCAASS)

Cronbach's α in our study for the Knowledge and Comfort scale was .95, for Approach .88 and for the Attitudes scale .76.

The mean scores (\pm SD) of all professionals for the Knowledge scale and Approach scale were 31.4 (\pm 8.5) and 9.6 (\pm 3.7) respectively. The mean scores on the Comfort and Attitudes scale were 63.0 (\pm 9.9) and 15.2 (\pm 1.5) respectively.

Sexuality Related Communication in Relation to Professionals' Self-Perceived Sexological Competence

The scores on self-perceived conversation skills of professionals who received a question about sexuality were significantly higher than those of professionals who did not receive such questions. The scores on self-perceived knowledge about sexuality and on self-perceived conversation skills of professionals who addressed the issue of sexuality were significantly higher than those of professionals who did not address this issue (Table 3).

Table 3 Mean self-perceived sexual competence and KCAASS scores for professionals who did or did not receive a question about sexuality, as well as for professionals who did or did not address the issue of sexuality themselves in the past 6 months

	How often did professionals receive a question about sexuality from patients?			How often did professionals address the issue of sexuality themselves when talking to a patient?		
	Never Mean \pm SD (n = 26)**	At least once Mean \pm SD (n = 10)**	<i>p</i> *	Never Mean \pm SD (n = 29)**	At least once Mean \pm SD (n = 7)**	<i>p</i> *
Self-perceived sexual competence						
Knowledge	4.6 \pm 1.8	5.8 \pm 1.1	.087	4.7 \pm 1.8	6.1 \pm .7	.049
Conversation skills	4.8 \pm 1.7 (n = 25)	6.4 \pm .8	.009	4.9 \pm 1.7 (n = 28)	6.7 \pm .5	.005
Recognition of sexual problems	4.4 \pm 1.7	5.4 \pm 1.4	.109	4.5 \pm 1.7	5.6 \pm 1.4	.131
KCAASS						
Knowledge	29.7 \pm 8.7 (n = 22)	35.2 \pm 6.8	.039	29.6 \pm 8.6 (n = 25)	37.9 \pm 3.8	.004
Comfort	60.3 \pm 10.7 (n = 19)	68.2 \pm 5.2	.021	61.3 \pm 10.3 (n = 22)	68.6 \pm 6.0	.048
Approach	9.1 \pm 3.6 (n = 19)	10.6 \pm 3.9	.164	9.5 \pm 3.8 (n = 22)	9.7 \pm 3.7	.672
Attitude	15.3 \pm 1.5 (n = 20)	15.0 \pm 1.6	.948	15.2 \pm 1.5 (n = 23)	15.0 \pm 1.7	1.000

* Mann–Whitney *U* test

** *n* Number of valid observations unless stated otherwise in the rows

Sexuality Related Communication in Relation to Professionals' KCAASS Scores

The scores on the KCAASS Knowledge and Comfort of professionals who did receive a question about sexuality or who did address the issue of sexuality were significantly higher than those of professionals who did not receive a question or did not address the issue themselves. The scores on the KCAASS Approach and Attitudes did not differ significantly among professionals (Table 3).

Discussion

In this study, only one out of five professionals working with patients with an ULD did address sexuality with their patients in the past 6 months. This low number is in strong contrast with the fact that more than half of the professionals believed that addressing sexuality was a part of their professional responsibilities. Even though this study is, to our knowledge, the first to investigate the sexuality related communication of professionals working with patients with an ULD, other studies focusing on different chronic diseases and/or disabilities have found the same contrast [23–25]. This duality can be explained by several reasons.

Firstly, the majority of professionals in our study (26/37) reported that they had not received any question about sexuality from their patients during the past 6 months. Previous research has shown that the lack of questions from patients might be interpreted by professionals as a sign that patients are not worried about sexuality issues or sexual problems [26]. As a consequence, professionals might decide not to address sexuality either. However, on their side many patients do not talk about sexuality or eventual sexual problems with professionals because they feel anxious [27], shy [28] or afraid of rejection [29]. It has been suggested that the non-discussion of sexuality between professionals and patients can be explained by a ‘conspiracy of silence’ [30], due to which sexuality remains a taboo between professionals and patients. This situation could also be characterized as a ‘waiting room culture’, referring to the fact that both patients and professionals are certain about the necessity to discuss the topic but are waiting for the initiative of the other party to open the discussion.

Secondly, compared to professionals in a previous study [21], the professionals working with people with an ULD are not really convinced about their own professional sexological competence, indicated by their rather low scores on the three aspects of self-perceived sexological competence. Their low self-esteem regarding addressing sexuality with their patients might withhold these professionals from actually doing so. This hypothesis is supported by the fact that professionals who did address sexuality had higher scores on self-perceived knowledge about sexual problems and self-perceived conversation skills. The same significant difference was found between professionals who did and professionals who did not receive a question about sexuality from patients. Apparently the professionals’ lack of confidence in their own sexological skills, is also noticed by the patients, causing them to remain silent about their sexual problems or concerns. This lack of confidence thus seems to contribute to the ‘waiting room culture’ mentioned above. In addition, the fact that the professionals who did address sexuality had higher scores on the KCAASS Comfort compared to the professionals who did not, confirms that professionals need to feel comfortable enough to address this sensitive topic. Not only being comfortable with sexual situations in general, but also being comfortable with one’s own sexuality is crucial for being able to address sexuality in a professional-patient relationship [31, 32]. Even though ‘becoming comfortable with sexuality’ and ‘feeling confident about one’s own sexological competence’ might not be easy attitudes to teach someone, studies have shown that when professionals perceive that they have received adequate courses and training on sexuality in general, they are more likely to feel comfortable to address sexuality in their job [33, 34]. Even though the professionals themselves do not seem to believe in their own abilities to address sexuality with their patients, the mean scores on the different KCAASS scales indicate otherwise. These scores were similar to those of other studies that used the KCAASS [15, 21, 22, 35]. The professionals who did address sexuality in the past 6 months had higher scores on the KCAASS Knowledge compared to the professionals who did not. Hence, increasing knowledge about sexuality might increase the chance that professionals will address sexuality with their patients. This was also reflected in the answers to the open question about how to improve the communication about sexuality. The majority of the professionals indicated that more knowledge about sexual problems of patients with an ULD is indispensable to be able to recognize and discuss eventual problems. Besides knowledge, many professionals in our study also reported the need for training in conversation skills and courses on how to address sexuality. This need for conversation or communication skills training was also brought up by other studies [36, 37]. Courses and training on sexuality for professionals working with patients with an ULD therefore seem to be a valuable addition to their current courses and training.

However, not only should individual professionals get courses and training on sexuality, attention should also be paid to the team’s approach towards communication about sexuality. In our study, sexuality or sexual problems of patients were seldom both formally

and informally discussed in the team or discipline group meetings. Many professionals also claimed that there were practical problems (e.g. no time, no room with enough privacy) that hinder a safe discussion of sexual issues with patients. Almost half of the professionals believed that the quality of attention paid to sexuality was inadequate and that improvements in the attention for sexuality in their departments could be achieved by systematically addressing sexuality with patients and within the team. One method to do so, could be use of standardised protocols. The protocol should address which team member(s) should take the responsibility for addressing sexuality with the patient. It should also contain timing for and frequency of addressing sexuality. Combined with appropriate courses and training about sexuality for professionals, this will hopefully create a climate in which sexuality becomes part of standard care for every patient with an ULD.

Study Limitations

The questionnaire used in this study, asked professionals to reflect on the past 6 months. Even though this is not an extensive period of time, it is possible that recall bias may have influenced the results of our study. Although the KCAASS has been used in other studies, the Dutch version of this questionnaire is not yet validated, which might be an aim of future research. It is likely that professionals who completely filled out the questionnaire were those who are most comfortable with the topic of sexuality. This would imply that the results of this study overestimated the actual situation concerning communication about sexuality in amputation departments. Notwithstanding the fact that a 47 % response rate is a good outcome in studies on sexuality, in this case the actual number of participants that completed the entire questionnaire was rather small ($n = 29$). The results, therefore, need to be interpreted with caution and may have a limited generalizability, but do show trends that should be thought about.

Conclusion

Sexuality is only scantily discussed by professionals working with patients with an ULD. Professionals indicated they do not feel confident nor comfortable enough to address this issue. To overcome the professionals' feelings of incompetence to talk about sexuality with their ULD patients, training and courses on sexuality seem to be valuable. In addition, a team protocol stating which team member(s) should address sexuality, as well as the timing for and frequency of this, is necessary for professionals to be able to address sexuality systematically. Appropriate facilities (e.g. a room with enough privacy) should be provided to facilitate professionals to talk about sexuality with their patients.

Acknowledgments Data collection was facilitated by the Working committee 'Amputation and Prosthetics of the Arm' (WAP-A) of the Netherlands Society for Physical and Rehabilitation Medicine (Nederlandse Vereniging van Revalidatieartsen; VRA).

Conflict of interest The authors declare that they have no conflict of interest.

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